



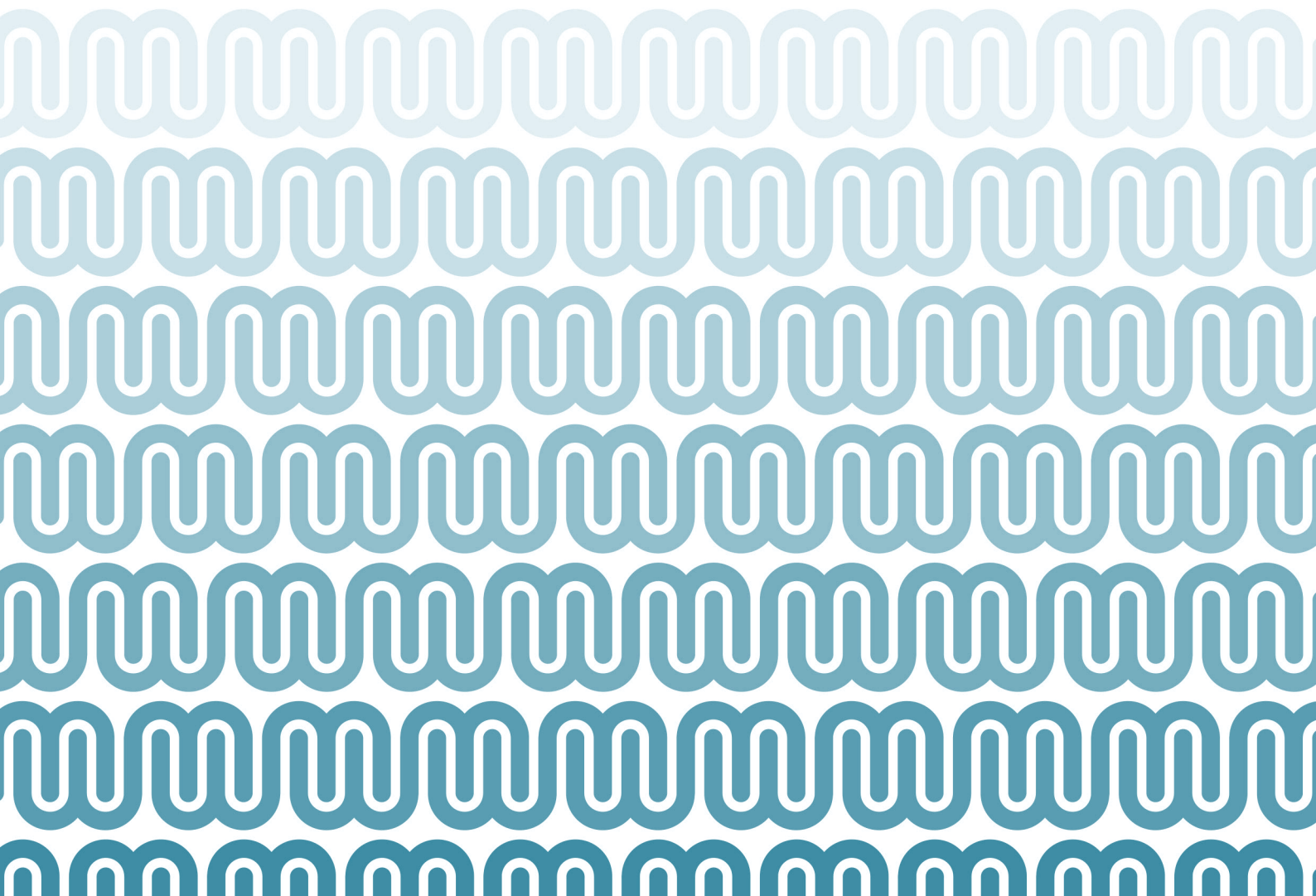
**mental welfare**  
commission for scotland

# **Learning Disabilities, Autism and Neurodivergence (LDAN) Bill: consultation response**

Corporate document

---

May 2024



## Learning Disabilities, Autism and Neurodivergence (LDAN) BILL: Consultation

### Respondent Information and Answer Return Form

Some sections of this consultation may be more relevant to particular individuals than others. Therefore, you may wish to only answer the questions or sections you find most relevant.

Please note the 'About You' section **must** be completed and returned with your responses. Questions marked with \* must be answered and we cannot accept your response if these are not correctly completed.

Please send this completed form to us by email or by post using the following details:

Our email address is: **LDAN.Bill@gov.scot**

Our postal address is: **FREEPOST – LDAN BILL**

(simply put form in an envelope and add address above – 3 words, all in capital letters - is all that is required to post your response free of any postage charge)

You can submit any written form of response this way too, so long as you have provided answers to the 'About You' section of this form, and in particular whether you would like your response to be published, and follow the flow of the questions, answering the questions as they are asked.

You are welcome to submit a response in an audio clip, video, or BSL video file – please email these to [LDAN.Bill@gov.scot](mailto:LDAN.Bill@gov.scot). You must again include answers to the 'About You' questions on pages 1-4, which can be accepted verbally. You are asked for a phone number and email so we may contact you if anything is missing and so that your responses can be accepted.

To find out how we handle your personal data, please see our privacy policy: <https://www.gov.scot/privacy/>

### About You

- Are you responding as an individual or an organisation?\* (*required*)
  - Individual
  - Organisation

- What is your name?

- What is your organisation?

If responding on behalf of an organisation, please enter the organisation's name here. If you are responding as an individual you can leave this blank.

- Phone number

Please provide a number we can contact you on in case any of your responses are unclear.

- Address

- Postcode\* (*required*)

Please provide so we can ensure we have a good representation across Scotland. Organisations should add an office postcode where possible.

- Email Address\* (*required*)

If you would like to be contacted again in future about this consultation please enter your email address here. You will also need to give permission to be contacted in the separate question asking this. Your email address will never be published.

- If you are responding as an organisation, please tell us which of the following categories best describes you (select all that apply)\* (*required*):

- Private sector organisation
- Public sector organisation
- Third sector organisation
- Disabled persons organisation(DPO)/Autistic persons organisation(APO)
- Other (please say)
- Not applicable - responding as an individual (see next question)

- If you are responding as an individual please tell us which of the following categories best describes you (select all that apply)\* (*required*):

- Neurodivergent person (i.e. autistic person, person with ADHD, person with a learning difficulty (i.e. dyslexia, dyscalculia))
- Person with a learning disability
- Family member or friend of a neurodivergent person or person with a learning disability
- Carer of a neurodivergent person or person with a learning disability

- Answering on behalf of a neurodivergent person or person with a learning disability (i.e. parent/guardian, support worker)?
- Neurotypical person
- Prefer not to say
- Not applicable - responding as an organisation (see previous question)
- Which ethnic group best describes you?
  - White Scottish
  - Other British
  - Irish
  - Gypsy / Traveller
  - Polish
  - Other white ethnic group
  - Mixed or multiple ethnic group
  - Pakistani, Pakistani Scottish or Pakistani British
  - Indian, Indian Scottish or Indian British
  - Bangladeshi, Bangladeshi Scottish or Bangladeshi British
  - Chinese, Chinese Scottish or Chinese British
  - Other Asian, Asian Scottish or Asian British
  - African, African Scottish or African British
  - Caribbean, Caribbean Scottish or Caribbean British
  - Black, Black Scottish or Black British
  - Other Caribbean or Black
  - Arab, Arab Scottish or Arab British
  - Other ethnic group
  - Prefer not to say
  - Not Applicable – responding as an organisation
- What was your age last birthday?
 

<input type="checkbox"/> 0 - 15	<input type="checkbox"/> 45 - 54	<input type="checkbox"/> 85 +
<input type="checkbox"/> 16 - 24	<input type="checkbox"/> 55 - 64	
<input type="checkbox"/> 25 - 34	<input type="checkbox"/> 65 - 74	
<input type="checkbox"/> 35 - 44	<input type="checkbox"/> 75 - 84	
<input type="checkbox"/> Not Applicable – responding as an organisation		
- Which local authority area you live in (or operate in if an organisation)?
 

<input type="checkbox"/> Aberdeen City	<input type="checkbox"/> Inverclyde
<input type="checkbox"/> Aberdeenshire	<input type="checkbox"/> Midlothian
<input type="checkbox"/> Angus	<input type="checkbox"/> Moray
<input type="checkbox"/> Argyll & Bute	<input type="checkbox"/> North Ayrshire
<input type="checkbox"/> City of Edinburgh	<input type="checkbox"/> North Lanarkshire
<input type="checkbox"/> Clackmannanshire	<input type="checkbox"/> Orkney
<input type="checkbox"/> Dumfries & Galloway	<input type="checkbox"/> Perth & Kinross
<input type="checkbox"/> Dundee City	<input type="checkbox"/> Renfrewshire

- East Ayrshire
- East Dunbartonshire
- East Lothian
- East Renfrewshire
- Falkirk
- Fife
- Glasgow City
- Highland
- Scottish Borders
- Shetland Islands
- South Ayrshire
- South Lanarkshire
- Stirling
- West Dunbartonshire
- West Lothian
- Western Isles (Eilean Siar)

- Which of these Options best describes how you think of yourself?
  - Heterosexual/Straight
  - Bisexual
  - Prefer not to say
  - Not Applicable – responding as an organisation
  - Gay/Lesbian
  - Other
- Which gender identity best describes you? Please only answer this question if you are aged 16 years or older.
  - Male
  - Non-binary
  - Prefer not to say
  - Not Applicable – responding as an organisation
  - Female
  - Other

**The following 2 questions MUST be answered so we can accept your responses.**

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:\* (*required*)

- Publish response with name
- Publish response only (without name)
- Do not publish response

**Information for organisations:**

The option 'Publish response only (without name)' is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are

you content for Scottish Government to contact you again in relation to this consultation exercise?\* (*required*)

Yes

No

## **Consultation Questions**

The questions in this document refer to information contained in our main consultation document [here](#). There are also alternative formats you can access.

You need only answer the sections most relevant to you and all answers in the Bill proposal sections should be provided voluntarily. The questions are mostly consistent throughout the sections and space is provided for your response – if you need more space, additional pages can be added.

### **Part 1: Reach and definitions: who should the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill include?**

#### **Who Should the Bill include?**

A Bill has to set out who it will apply to and in what circumstances. This means our Bill has to say which groups of people it will apply to.

This is important because it sets out who can benefit from the Bill's provisions, and who can rely upon it to uphold their rights or seek redress for their rights being breached.

If the people included are not properly defined, the legislation won't be able to fully benefit the people it is intended for.

#### **What can the LDAN Bill do?**

There are 3 different potential approaches for this Bill.

#### **Proposal 1: 'People who are Neurodiverse'/'Neurodiverse People'**

There are differing schools of thought in academic literature about what 'neurodiversity', and 'neurodiverse' means.

We understand that it is, however, commonly accepted that 'neurodiversity' encompasses all of humanity, and does not mean 'neurological disability' or 'otherness'. 'Neurodiversity' describes a population, not individuals. A person cannot, therefore, be individually 'neurodiverse'.

If we use the term neurodiverse in the Bill then it may be too broad. It will cover the whole population including people who are not neurodivergent - 'neurotypical' people - so we don't think it is a good description to use in the Bill.

### **Proposal 2: 'People who are Neurodivergent'/Neurodivergent People'**

We understand that it is commonly accepted that 'neurodivergent' means having a mind that functions in different ways to the minds of the majority of people in society.

'Neurodivergent' and 'neurodivergence' are very broad terms that would allow us to capture a wide range of people within the Bill, including people with learning disabilities, people with learning difficulties such as people with dyslexia, dyspraxia and dyscalculia, autistic people and people with Down's Syndrome, Attention Deficit Hyperactive Disorder (ADHD), and Fetal Alcohol Spectrum Disorder (FASD). However, the term can also apply to people with acquired brain injuries.

We could also consider how to put some further definitions in the Bill around how we define "neurodivergent" to ensure that it does not become too wide.

Such an approach could allow us to define neurodivergence by reference to common barriers or behaviours faced or expressed by various groups. This would be similar to the approach taken by the Education (Additional Support for Learning) (Scotland) Act 2004, where a child or young person does not require a diagnosis to be able to receive support.

### **Proposal 3: including specific conditions only in the Bill**

We could take an approach that specifically names and defines populations of people in the Bill. This would increase the visibility of these groups and more clearly state who the Bill applies to for the benefit of those people, as well as for practitioners.

For example, we could choose to apply the Bill only to people with a learning disability and autism; add ADHD and FASD; or any combination of neurodivergent conditions. However, if a condition was not specifically listed and defined, then that population would be excluded.

The Bill could include a power that allows future changes to the Bill's definitions to be made by Regulations, as our understanding of neurodivergence and different conditions evolve. This means that, if certain conditions were left out of the initial Bill, they could potentially be added later, after the Bill has become law.

There is also a question about whether Down's Syndrome should be specified separately from broader learning disabilities – we understand that some people will support this and some will not.

## What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why? If the people included are not properly defined, the legislation won't be able to fully benefit the people it is intended for.

Proposal 2 refers to the Education (Additional Support for Learning) (Scotland) Act 2004 where, "for whatever reason, the child or young person is, or is likely to be, unable without the provision of additional support to benefit from school education provided or to be provided for the child or young person".

The focus on 'for whatever reason', that is, needs rather than diagnosis is welcome. Individuals can have more than one diagnosis; they can wait a long time for that diagnosis, the diagnosis can change over time and sometimes unique individuals simply do not 'fit' within the diagnostic definition and may fall between supports and services as a result. The setting of boundaries based on need, barriers faced, circumstances and behaviours rather than a medical model of disability is in keeping with other legislative reform intentions.

Neurodivergence however can mean different things to different people so some clarity and definition will be required, as strengthened rights and any additional resources may not be realised without these.

The Commission is also aware that stakeholders are looking for both clarity and visibility for particular groups within the Bill.

We know, for example, that the needs of people with learning disability and autistic people have not been addressed through wider mental health policy and reform going back to recommendations from the Millan Committee to consider the place of people with learning disability and autistic people in legislation, the Rome Review and the slow progress towards the 2018 Coming Home and subsequent Coming Home Implementation Framework recommendations. Additional significant health inequalities identified in the original Health Needs Assessment research and subsequent update report. Data coming from learning disability and autism reviews elsewhere show the significant morbidity and mortality faced by these groups.



“People with learning/intellectual disabilities have some of the poorest health of any group in Scotland and die on average twenty years earlier than the rest of the population. This year, new evidence was published by the Scottish Learning Disabilities Observatory that tells us children with learning/intellectual disabilities are at least 12 times more likely than other children to die in childhood and adults with learning/intellectual disabilities are twice as likely to die from preventable illnesses”. Learning / Intellectual Disability and Autism Towards Transformation March 2021.

[Learning/Intellectual Disability and Autism Towards Transformation \(www.gov.scot\)](http://www.gov.scot)

It is therefore suggested that any Bill needs to be clear on its intent to progress and enhance the lives of people with learning disability and autistic people and explicitly identifying these two groups of people in the terminology will be helpful in providing that focus.

People with Down Syndrome would be included as one of many conditions that can lead to learning disability; we do not support this as a separate definition. Other populations will also be included within the definition of learning disability where they have additional diagnoses such as foetal alcohol syndrome when it is associated with significant cognitive impairment. Individuals with the same diagnoses can have diverse needs hence the focus on needs remains important.

The explicit identification of people with learning disability and autistic people as suggested is not intended to exclude other groups of people who share similar difficulties in living their lives and accessing services.

It would be considered that the proposals included within this Bill that are intended to be of benefit to people with learning disability and autistic people will also bring benefit to people with a diverse range of other conditions where they face similar challenges.

Whilst our response to this consultation does focus on people with learning disabilities and autism because it is these people we work more closely with currently, this is not to exclude others who also have needs which require to be addressed as part of this Bill.

Which of these proposals do you **not agree** with (if any), please tell us why?

Proposal 1: such a broad definition is at risk of diluting any benefit intended.

Is there anything else that we should consider in relation to this topic?

The Mental Welfare Commission's role is to protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

We know that people with learning disability and autistic people are at increased risk of a range of conditions leading to increasing complexity which further impacts on their ability to lead an ordinary life, access services and meet health and social care needs. This includes a group of people who, even with the appropriate supports, are unable to make decisions about their care and treatment.

A tiered model approach to all aspects of this Bill may be helpfully considered to meet the diverse needs of people including those with learning disability and autistic people. This would be in keeping with the whole system model and Support, Care and Treatment Pathways proposed in the Mental Health and Wellbeing Strategy.

[No-wrong-door vision-for-MH-learning-disabilities-and-autism-services-in-2032.pdf \(nhsconfed.org\)](https://www.nhsconfed.org/no-wrong-door-vision-for-mh-learning-disabilities-and-autism-services-in-2032.pdf)

Such a model recognises that there are many ways that people with learning disability or autistic people are prevented from living an ordinary life and takes a whole life and whole system approach to addressing this.

e.g. The majority of people will benefit from access to accessible information whilst some individuals will require a more specialist advocacy service.

e.g. The majority of people with learning and disability and autistic people would benefit from services where staff have received mandatory training and are better informed. Better informed services may, by extension, be better able to meet the needs of other populations of people who share similar difficulties in accessing services, be that a person with dementia or someone with cerebral palsy etc.

It also recognises that some people will benefit from additional support at key times in their life and they may require more specialist or focussed support at those times.

e.g. Supporting people at those key times could mean ensuring early intervention, a coordinated person-centred approach to transitions between adolescent and adult services or access to specialist advocacy when a person needs support to navigate services and make decisions about their life.

People with learning disability and autistic people are at increased risk of a range of health conditions including additional developmental and communication conditions, sensory needs, physical illness and mental ill health. With increasing complexity there is a need for additional and often more specialist services. In such instances it would be expected that staff teams have more focussed and specific training and more specialist knowledge and experience.

e.g. Access to a specialist non directive advocate for an individual who has no verbal communication; positive behaviour support training for health and social care services providing direct care and sensory adaptations to inpatient services.

A small number of people will require care and treatment in highly specialist services due to multiple and complex needs. In such situations people with learning disability and autism may be subject to mental health and capacity legislation where they are unable to make decisions about their health and well-being even with communication support and specialist advocacy to support decision making. This small group represents some of the most vulnerable people receiving health and social care and they will require the greatest safeguards.

e.g. Highly specialist environments (including inpatient environments) that are sensitive and flexible to the sensory and developmental needs of people with learning disability and autistic people who have significant ill health, local policies regarding the use of restrictive practices and national guidance regarding the rights of people who are unable to make decisions when all reasonable adjustments and supports to decision making have been made.

The consultation scope has been set broadly and the ambition of any Bill that results may reflect this. We consider that a national strategy that might follow from this (see below) should focus initially on health inequalities that many people face.

## **Part 2: Overarching Themes**

### **Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities**

The Scottish Government has previously produced national strategies on learning disability and separately on autism. Following the COVID pandemic, a joint plan produced in partnership with Convention of Scottish Local Authorities (COSLA) was published covering both learning disabilities and autism – the *Towards Transformation Plan*. The Scottish Government

continues to work to this plan pending decisions on the shape and content of the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill.

Scottish Government strategies are scrutinised by the Scottish Parliament and stakeholders. There is currently no formal or legislative requirement for either national or local strategies specifically for neurodivergent conditions or learning disabilities.

### **What can the LDAN Bill do?**

The Scottish Government is proposing to take a broad approach covering neurodivergence and learning disabilities.

We recognise that approaches to previous strategies and policies have been single condition focussed even although many people have more than one condition. Although there will always be a need for some distinct policies according to certain conditions, we think a wider neurodivergent approach is more appropriate in terms of recognising the whole person rather than single conditions and recognising the crossover in the way services and supports are delivered. This includes the workforce delivering them.

There should also be a clear recognition that neurodivergent people and people with learning disabilities should be treated equally whatever condition or combination of conditions they have.

**Proposal 1:** Introduce a requirement for a national strategy on neurodivergence and learning disabilities to be produced by the Scottish Government.

**Proposal 2:** Introduce a requirement for local strategies to be produced by some public bodies, for example health and social care partnerships, local authorities, and other public bodies.

**Proposal 3:** Introduce guidance that could cover a range of topics to be included in national and local strategies.

**Proposal 4:** Ensure that there is a requirement to review strategies, for example every 5 years for example.

**Proposal 5:** Ensure that people with lived experience have to be involved in the development of the strategies.

**Proposal 6:** Consider whether any new accountability mechanism introduced by the Bill should have a duty to review national and/or local strategies and their effectiveness.

## What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1: A National Strategy on Neurodivergence and Learning Disability.

Many aspects of the current MH & Well Being Strategy are relevant and welcomed to improve the care and treatment of people with learning disability and autistic people, across their lifespan.

The intention for a 'strategy for everyone' is noted and some of the issues raised within the strategy are real issues for people with learning disability and autistic people:

- ☑ A need for a stronger focus on prevention and early intervention.
- ☑ The importance of tackling poverty and inequality.
- ☑ Supporting person-centred and whole family approaches.
- ☑ A need for increased community-based support and services.
- ☑ Increased and longer-term funding for mental health and wellbeing services, including for the third sector.
- ☑ Growing the workforce – developing a skilled and diverse mental health and wellbeing workforce which can operate at safe levels, and addressing talent attraction, recruitment and retention challenges.

Research undertaken in Scotland in the last 2 decades, including the initial Health Needs Assessment report and subsequent update and via the Coming Home report and Implementation Framework, highlights the significant health inequalities faced by people with learning disability in Scotland. Around 1 in 15 people with learning disability also have a diagnosis of autism.

[Epidemiology of mental health problems in adults with learning disability: an update | Advances in Psychiatric Treatment | Cambridge Core](#)

The first data from Annual Health Checks programme will provide some information about the numbers of deaths and cause of death of people with learning disability in

Scotland, but it is not clear when all the HSCPs will have established this programme by.

The following data is taken the Learning from Lives and Deaths – people with learning disability and autistic people (LeDeR) 2022 report:

In 2022 there were 3648 unique deaths for people with learning disability  
42% of deaths were considered to be avoidable (versus 22% in the general population)

57% died in a hospital setting

The commonest causes of death were: circulatory diseases - 16.7%; respiratory diseases - 14.6%; neoplasms - 14.5%, nervous system - 13.6%, congenital & chromosomal disorders 13.3%, digestive system – 7%

3.7% of people died of mental disorders (includes dementia and delirium)

This compares with the 5 commonest causes of death in the general population as being dementia (11.4%), ischaemic heart disease (10.3%), respiratory diseases, cerebro-vascular disease and cancer.

Where there were problems with care, the most commonly identified issue was with organisational systems and process.

[Learning from Lives and Deaths - people with a learning disability and autistic people \(LeDeR\) - King's College London \(kcl.ac.uk\)](https://www.kcl.ac.uk/lede/)

The Health Needs Assessment identified that public health measures intended for the whole population will not improve health inequality and, if anything, are likely to widen the health inequality gap.

A national strategy is required to fully recognise the health inequalities faced by people with learning disability and autistic people, understand the data about their specific needs and high levels of unmet needs and ensure that there is a consistent approach to service design and service delivery across Scotland.

The health inequality data cannot be ignored. It is considered further in Part 3 Section 1 but remains a key priority for any national strategy.

Broader human rights are considered in the relevant sections of this consultation.

Any national strategy should be guided by a set of principles identified in partnership with people with lived experience and in keeping with human rights principles.

In addition to the issues raised in the Mental Health and Well Being strategy and already raised within this consultation there are a number of specific issues to highlight:

Health inequality – see Part 3 Section 1

Early intervention – access to diagnosis in child and adolescence that allows early intervention (and includes formal cognitive assessments rather than a focus on educational needs of primary and secondary school which do not meet needs through transition in to adulthood) and person-centred planning that looks beyond educational settings in to adulthood.

Transition processes including better monitoring of individuals delayed in adolescent services awaiting appropriate housing and support in adult services

Single point of contact/ no wrong door approach – recognising the barriers to care

Employment and meaningful vocational activities – health and social care services should have a leadership role in creating opportunities in conjunction with relevant groups and organisations.

Crisis & respite services – that offer meaningful activities in healthy environments including access to respite when it is needed in emergency situations.

Contingency planning including additional funding when required.

A national approach to commissioning supported by information identified via Dynamic Support Register processes and the need for a diverse range of services across Scotland at all levels. Linked with requirements for local authorities to have anticipatory housing strategies and commissioning in response to local data.

e.g. appropriate housing and support in local areas, including services which are skilled at supporting people when distressed or displaying behaviours that challenge

e.g. inpatient forensic services and services for people who display complex and severe behaviours that challenge and recognising current gaps in service provision notably female low secure and equivalent services.

e.g. highly specialist services such as specialist autism inpatient service within Scotland.

### Mental Health Service Quality Standards Consultation

The mental health service quality standards consultation paper does not make specific reference to secondary care services for people with learning disability and autistic people. The needs of people with learning disability and autistic people in secondary care services, be that general services or specialist services requires specific consideration to ensure environments that are healthy and do not increase distress and morbidity. Please see links below that describe the standards and some considerations from other jurisdictions regarding environment.

[Adult Secondary Mental Health Services Consultation \(www.gov.scot\)](http://www.gov.scot)

### Capable Environments | bild

[NHS England » The learning disability improvement standards for NHS trusts](#)

[qnld-fourth-edition-standards.pdf \(rcpsych.ac.uk\)](http://rcpsych.ac.uk)

Quality Network for Learning Disability Services (QNLD) Standards for Inpatient Learning Disability Services covering the following standards:

Admission and assessment • Care Planning & Treatment • Referral, Transfer & Discharge • Patient & Carer Experience • Environment & Facilities • Staffing & Training • Governance

The Mental Welfare Commission for Scotland has undertaken themed visits to review the care and treatment of specific populations of people with learning disability and autistic people. The range of recommendations reflects the complexity of care needs, the number of organisations that are involved and includes issues that would be highly relevant to a National Strategy.

### Autism and complex care needs. October 2019.

This was a themed visit specifically looking at support for autistic people. 54 people were visited in hospital and community settings, including specialist autism services in England. Carers and professionals were involved. There were recommendations to:

*NHS Boards:* to ensure that people with autism have comprehensive assessment and diagnosis and individualised environmental and sensory assessments whenever a person with autism is admitted to a psychiatric setting.

*Integration Authorities:* to have a dedicated care co-ordinator overseeing evidence-based treatment via a tailored activity plan, support for families with the offer of a carers assessment, post diagnostic support with involvement of people, carers and families and arrangements to secure community provision for people



with autism in hospital within 6 months of their being assessed as able to be supported in the community.

*The Scottish Patient Safety Programme:* to develop a programme to reduce the use of psychotropic medication for autistic people for the management of behaviours perceived as challenging and to reduce levels of restraint.

*NHS and community services:* to maintain policies regarding the use of restraint and seclusion and to develop improvement plans to reduce their use.

*Scottish Government:* to monitor delivery of the above recommendations.

There were additional recommendations across services regarding training needs and clinical supervision of people providing services to people with autism and complex needs.

[ASD Theme Visit Report-20191030.pdf \(mwcscot.org.uk\)](https://www.mwcscot.org.uk/ASD-Theme-Visit-Report-20191030.pdf)

No through road: People with learning disabilities in hospital.

The Commission visited all 18 hospital units for people with learning disability (excluding forensic units) from August to October 2015 and during this time examined the records of 104 people, met with 46 people individually and heard from 6 other people via other means. During the visits we reviewed delayed discharges and discharge planning, the legal basis for treatment and any restriction on people's freedom. Users of the services and their carers were consulted about issues that were important to them including maintaining skills, activities, participation and involvement and the environment in the units.

Recommendations were made across quality of life (delayed discharges, specialist assessments & skill development), environment (all learning disability inpatient units are fit for purpose), rights and restrictions (including risk assessments, restrictive interventions & specified persons), health needs (annual health checks, use of AWI and Section 47 certificates and treatment plans) and participation and engagement (accessible information, advocacy, involvement of users and carers).

[no through road.pdf \(mwcscot.org.uk\)](https://www.mwcscot.org.uk/no-through-road.pdf)

Proposal 2 Local Strategies

As set out in national policy.

Supported by Good Practice Guidance as per Proposal 3.

To ensure a consistent approach across Scotland and equity in care.

Duties re data reporting.

## Proposal 3 Guidance

Clear guidance that supports local and national services and which links with training provision discussed in Section 2 is important in developing a skilled workforce and ensuring the needs and rights of people with learning disability and autistic people are met.

A collaborative approach between health and social care organisations, lived experience and family & carer groups and relevant other bodies including NHS Education for Scotland and Health Improvement Scotland.

**The Mental Welfare Commission for Scotland** produces good practice guides to support best practice across a wide range of areas of interest such as social circumstances reports, excessive security, tenancies, advocacy and supported decision making. The Commission website also provides answers to questions that individuals who have experience of care and treatment, members of the public, carers, and professionals have asked us.

### *Rights in Mind*

This pathway is designed to help staff in mental health services ensure that patients have their human rights respected at key points in their treatment.

[Rights in Mind | Mental Welfare Commission for Scotland \(mwscot.org.uk\)](https://www.mwscot.org.uk)

### *Right to Treat*

When someone lacks the capacity to provide consent, it is vital to ensure that there is a clear basis on which treatment takes place both for the healthcare professional providing the treatment and to safeguard the rights of the person. This guidance provides information to determine the basis on which to proceed or not.

[Right to treat \(mwscot.org.uk\)](https://www.mwscot.org.uk)

### *Use of Seclusion*

The Mental Welfare Commission guidance is for health and social care professionals working with people who are being treated for mental illness, dementia, learning disability or related conditions in health and social care settings. This guidance is for situations where those professions may be considering using seclusion and also considers seclusion in special situations in keeping with 'long term segregation'.

[Seclusion GoodPracticeGuide 20191010.pdf \(mwscot.org.uk\)](https://www.mwscot.org.uk)

### Vaccination for people with mental illness, learning disabilities, dementia and associated conditions

Research has shown that people with mental health difficulties that might underlie reduced capacity are at greater risk of Covid-19. The concern is that people who are

unable to consent to the vaccine and are resisting should not be disadvantaged because of any uncertainty about how to proceed in these situations. The wish to ensure that people who are resisting vaccine due to a lack of capacity to consent are treated with dignity and in accordance with the principles of the 2000 Act led to review and update the guidance note for practitioners.

[CYFARFOD BWRDD IECHYD \(mwcscot.org.uk\)](http://mwcscot.org.uk)

### **Mental Welfare Commission Advice Line**

The Commission, within the remit of the 2003 Act 2003, Sections 9 and 10, operates an advice line, open to professionals as well as individuals and carers/ relatives/welfare guardians. The advice line receives about 4000 calls each year. A review of the advice lines found that the Commission received calls about a wide range of topics. A higher proportion of calls to the advice line come from non-professionals, just under half of the calls related to legal issues and 13% of all called related to ethical issues, 6% to moral issues and 4% were about financial issues. The advice line serves a wide range of people phoning about many different topics and suggests that this unique service provided in Scotland is a point of call for many to get independent advice about ethical, legal and general issues related to mental health.

[2022-04 AdviceLineCalls-brief.pdf](#)

### Proposal 4 Regular Review

To ensure progress against recommendations and continued evaluation of some of the processes identified through this consultation process which are in their early stages and where data is only beginning to emerge i.e. Dynamic Support Register and Annual Health Checks.

### Proposal 5 Co-Production Lived Experience

Yes

[NHS England » Nothing about us, without us](#)

### Proposal 6 Accountability Mechanism

The Mental Welfare Commission for Scotland is committed to being a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected and have the appropriate support to live the life of their choice.

Strategic priorities include a focus on the most vulnerable; there are robust processes to identify and respond to the needs of people who are less likely to have their voice heard and where their human rights are not being upheld.

The statutory Advisory Committee of the Commission's board informs the work of the Commission in the learning disabilities and autism fields with representation from national bodies including Enable, Learning Disability Nurses Forum & National Autistic Society.

Extending and strengthening the role of the Mental Welfare Commission for Scotland is discussed in more detail in Part 4 Accountability and is our preferred model that would reduce the complexity across the landscape.

This could occur in parallel with the identification of a senior learning disability and autism adviser in Scottish Government discussed below.

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to strategies?

Recommendation:

Senior Learning Disability & Autism Office/r in Scottish Government who has an advisory role in addition to monitoring and progressing priorities as outlined with national strategy in collaboration with key partners. This would be informed by data from the Annual Health Check, LeDeR equivalent data and data from Dynamic Support Register.

Any such adviser would need clearly defined links across health and social care to capture the broad intentions of this Bill.

A focus on physical health and health inequality is considered a priority.

Addressing the gaps in health and social care services, particularly for people who require highly specialist services is also needed. This will ensure that people with learning disability and autistic people who have the most complex health and social care needs are able to access the services that they require. It will also increase the capacity of health and social care teams to focus on their core functions including prevention and early intervention.

For a small group of people who have mental ill health in addition to learning disability and autism, and where they are unable to make decisions about their care and treatment with support the Mental Welfare Commission for Scotland, in conjunction with other safeguarding bodies, has statutory duties to ensure that the rights of this group are safeguarded. The duties and activities of the Mental Welfare Commission for Scotland can be strengthened and extended via the proposed Bill – this is considered in more detail in Part 4.

[Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs \(www.gov.scot\)](http://www.gov.scot/coming-home)

Some of the outstanding recommendations from the Coming Home processes remain highly relevant to the intentions of this Bill and development of local and national strategy.

#### Theme One: Strengthening Community Services

Recommendation 1: Develop options for access to crisis services for people with learning disabilities and complex needs, with a view to providing direct support to service provider or family placements which are at risk of breakdown.

Recommendation 2: Consider the role of flexible support responses, to be used when placements are experiencing significant difficulty. The need for this should be informed by the use of risk registers to identify individuals at risk of out-of-area or hospital placement.

Recommendation 3: Ensure that greater consideration is given to family support for the family carers of people with learning disabilities and complex needs.

#### Theme Two: Developing Commissioning and Service Planning

Recommendation 4: Take a more proactive approach to planning and commissioning services. This should include working with children's services and transitions teams; the use of co-production and person-centred approaches to commissioning; and HSCPs working together to jointly commission services.

Recommendation 5: Identify suitable housing options for this group and link commissioning plans with housing plans locally.

#### Theme Three: Workforce Development in Positive Behavioural Support

Recommendation 6: The Scottish Government should seek partnership with a university to provide PBS training across the health and social care workforce in relation to people with learning disabilities and complex needs.

Recommendation 7: The Scottish Government should support the establishment of a PBS Community of Practice

## **Section 2: Mandatory Training in the Public Sector**

One of the key themes we have heard through our scoping exercise, and from stakeholders and the Lived Experience Advisory Panel (LEAP), is that that there needs to be greater awareness, training on, and understanding of neurodivergent people and people with learning disabilities. In particular, there is a need for this when people are trying to access help, support and services and to exercise their rights.

Whilst there can be training options available to public sector professionals to help them to better understand and communicate with neurodivergent people and people with learning disabilities, undertaking this training is voluntary and is not necessarily developed or delivered by people with lived experience. This means that people who work in public services, such as in the National Health Service (NHS) or social care, the police and prisons, can choose to do training or not, if it is available to them. It is not consistent across different public services or delivered to a standard. It can vary in quality and effectiveness.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

Having access to staff in public services who are informed and able to understand and communicate with people effectively can make a significant difference:

- People are more likely to engage with services
- People are more likely to seek help and support at an early stage meaning crisis can potentially be avoided
- Staff will feel more confident in meeting needs successfully
- Early engagement with health and social care supports will allow a greater focus on prevention and reduce health inequalities

### **Proposal 1: Mandatory Training for Public Services**

We want to consider how we make training mandatory for public facing staff in some public services.

In the first instance, we would like to consider implementing the same approach as in England, by placing a mandatory training requirement on health and social care staff.

However, we could also consider extending this to other public sector areas. For example, the justice system, which could include the police and prison staff, and in the education system for teachers and other educators. Although the approach in England relates specifically to training on autism and learning disabilities, we could consider a broader approach for training to be inclusive of neurodivergence more generally, as well as learning disabilities.

As part of our approach to mandatory training we want to think about how people with lived experience should be involved.

### **What Do You Think?**

Do you **agree** with this proposal, please tell us why?

Yes.

Ensuring that health, social work and social care staff have an understanding of the difficulties faced by people with learning disability and autistic people is important in increasing awareness and supporting access to services. It would also be important to then roll-out training across other aspects of the public sector such as housing officers, criminal justice workers, benefits advisors etc.,

A national approach is valuable in ensuring consistency across Scotland and equitable care.

Training should be produced in co-production with people with lived experience and family & carer groups to ensure that it focusses on key issues.

Evaluation of the impact of such a strategy in building a skilled work force and improving access to services is equally important to ensure the most effective use of resources.

A national training strategy could be supported by a no wrong door approach which aims to reduce the number of steps a person with has to make will also support access to services.

A national framework with minimum mandatory requirements or competencies and additional training relevant to clinical role, profession or specific service may be helpful.

e.g. Introductory training may cover broad themes such as how learning disability and autism present; the impact of sensory, communication and ill health in these groups and how to support access to services. Such introductory training is likely to consider key issues which would be relevant or valuable when supporting people with other neurodivergent conditions.

e.g. Mandatory training across health services might include Equality and Diversity, Adults with Incapacity Act, Adult Support and Protection, Child Protection, Criminal Procedures Scotland Act, MAPPA, MARAC and public protection.

e.g. More specialist training may be required in medical or psychiatric settings regarding the different ways that illness can present in people with, for example, learning disability and autistic people.

e.g. Specialist learning disability or autism services will require far greater knowledge and expertise and this will be delivered via postgraduate training programmes. The potential list of additional training that would be relevant to this group is lengthy, but examples might include human rights training, support for decision making or positive behaviour support models.

e.g. Certain professional groups are required to attend specific training which includes:

AWI – Section 47 training to allow completion of a certificate of capacity.

MHA – Advanced Medical Practitioner training 5 yearly.

Specialist Mental Health Officer training.

Existing training resources that are already available and/ or under development by A range of organisations could also be considered within a competency framework. These include:

#### NHS Education for Scotland (NES)

NES have collated a range of resources on the TURAS learning platform. Content includes improving outcomes for people with learning disabilities, equal health, psychological care, supporting behaviours perceived as challenging, trauma, children, young people and families, annual health check resources, COVID-19 and people with learning disabilities and a number of webinars and masterclasses.



NES is also responsible for developing and delivering healthcare education and training for NHA, health and social care sector and other public bodies with a Scotland wide role in undergraduate, postgraduate and continuing professional development.

Through the TURAS learning platform training is provided regarding autism and neurodiversity across the lifespan and links to [Different Minds. One Scotland](#) a Scottish Government website written in partnership with autistic people where facts and myths about autism are explored and comments and accounts from people with lived experience of autism are presented.

[Different Minds | Autism Scotland](#)

There are also links to the Scottish Government Keys to Life Implementation Framework and Towards Transformation, the autism and learning/ intellectual disability transformation plans.

[Once for NES : Learning Disabilities | Turas | Learn \(nhs.scot\)](#)

#### Mental Welfare Commission for Scotland

The Commission has developed an Adults with Incapacity Act Masterclass in partnership with NES which is being provided via the Once for Scotland – Adults with Incapacity Turas learning site. The masterclass sessions are aimed at health, social work and social care professionals working with adults. They examine key aspects of the AWI and including the principles, deprivation of liberty and possible actions.

[New TURAS Learn Zone – Adults with Incapacity | NHS Education fo \(scot.nhs.uk\)](#)

The Commission also produces a range of good practice guidance which are referred to in Part 2 Section 1 and Part 4.

The Oliver McGowan Mandatory Training on Learning Disability and Autism is an e-learning session co-created and delivered with experts by experience. The evaluation report is included and identifies that one of their introductory programmes has evidence for use.

[OMMT-final-report.pdf \(ndti.org.uk\)](#)

#### The British Institute of Human Rights Training

The British Institute of Human Rights provide training for individuals & communities and for public bodies through workshops, resources and knowledge and confidence building programmes.

[Human Rights Training | British Institute of Human Rights \(bihr.org.uk\)](#)

It is also important to consider the specialist learning disability nursing and specialist intellectual disability psychiatrists and ensuring that there are appropriate numbers of these skilled professionals. The influence of these roles in raising awareness and standards through their work is important to consider with regards raising overall standards.

Do you **not agree** with this proposal, please tell us why?

Is there anything else that we should consider in relation to mandatory training?

A national training strategy could be supported by a no wrong door point of entry to services approach which aims to reduce the number of steps a person has to take to access services.

[No wrong door | NHS Confederation](#)

### **Section 3: Inclusive Communications**

Inclusive communication means sharing and receiving information in a way that everybody can understand. For public authorities and people who provide support and services, it means making sure that they recognise that people understand and express themselves in different ways. For people who access support systems and services, it means getting information and expressing themselves in ways that meet their needs. Inclusive communication relates to all modes of communication: written information, online information, telephone, face to face.

Neurodivergent people and people with learning disabilities with communication support needs can face widespread exclusion and disadvantage. The use of inclusive communication is vital in order to allow people to know and exercise their rights, to live independently and to participate fully in life.

**What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

The Bill could assist by providing a stronger focus on how public authorities' duties around inclusive communication can best be met for neurodivergent people and people with learning disabilities – potentially providing more specificity than the Human Rights Bill (recently consulted upon) and existing public sector duties. The provision of more accessible information links also to our proposals on training. Inclusive communication would inherently be a significant component of that training.

Although we focus on public bodies for the Bill, it will also be important to think about how we extend and promote inclusive communications to other organisations in the future. Some or all of the following could be explored further for possible inclusion in the Bill.

### **Proposal 1: Alternative means of communication**

Provide for neurodivergent people and people with learning disabilities to request access to alternative means of communication where the offered means of communication will not work for them. This could mean being able to request an online or telephone meeting rather than face to face, or a telephone call instead of a letter, or other forms of communication.

It might also be appropriate for neurodivergent people, and people with learning disabilities, to be able to request access to a practitioner with specialist training in certain circumstances. For example, when accessing health care or when navigating the criminal justice system.

### **Proposal 2: Easy-read**

Better access to easy-read versions of all public facing communications and documents made by public authorities. This could include a broad duty to make them available on request and an automatic duty to provide them in certain circumstances, such as:

- a duty on National Health Service (NHS) Boards and Health & Social Care Partnerships (HSCPs) to require appointment letters to automatically be produced in easy read; and
- a duty on the Scottish Police Service, the Scottish Courts and Tribunal Service and the Scottish Prison Service to automatically provide information to people in certain circumstances including when accused or convicted of a crime in an accessible way, including standard bail conditions.

There will be other circumstances too where an automatic duty would be important.

### **Proposal 3: Neurodivergent and learning disabilities strategies**

Local and national strategies are discussed more fully in a previous section. If the Bill were to require local strategies to be produced, this could apply to local authorities, NHS Boards and integration authorities, and potentially other public bodies if appropriate. The Bill could provide the Scottish Government with power to direct what these strategies should cover and this could include how communication needs are met.

### **Proposal 4: An enforceable Accessible Information Standard for Scotland**

Whilst the Accessible Information Standard made under section 250 of the 2012 Act is not enforceable in Scotland, guidance sets out that it should be considered best practice in NHS Scotland organisations. The Bill could provide for an Accessible Information Standard to be enforceable in Scotland with requirements for its implementation and impact to be reviewed.

### **What Do You Think?**

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1 Alternative Means of Communication

Yes.

Supporting people to engage via their preferred method will be beneficial in supporting them to be able to engage as well as possible.

This could be extended to including the person being supported by a preferred family member, carer, advocate or support worker.

As is the case across this consultation there should be recognition that when, for example, someone with learning disability or an autistic person has additional developmental, learning, communication and sensory conditions there is the need for increasingly specialist services. The same is true for communication.

Examples include where a person with learning disability or an autistic person has an additional sensory condition leading to hearing or visual loss; where an individual does not use verbal communication or people from minority ethnic groups whose first language is not English.

Should also consider the needs of young carers who may be called upon to support communication with their parents or other family members when they are trying to access services.

## Proposal 2 Easy Read

Yes

Creation of easy read and accessible information requires specialist knowledge and experience in collaboration with lived experience groups.

Multiple services creating easy read and other accessible versions of standard duplication is likely to lead to significant unnecessary duplication and lack of a consistent approach.

## Proposal 3 Neurodivergent and LD Strategies

Yes.

Direction as to the context of local strategy is important in ensuring consistency across the country.

The involvement of people with lived experience is important in any such process.

## Proposal 4 Enforceable AISS

This would be valuable in progressing the availability of accessible information across services.

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to accessible information?

There would be value in taking a collaborative approach to ensure the development of consistent and high standard resources. This would also prevent unnecessary duplication.

Co-production with lived experience groups to ensure that accessible information is appropriate, sensitive and respectful.

It is noted that one action of the Towards Transformation plan relates to accessible information: Action 29 - In partnership with the Scottish Commission for people with Learning Disabilities (SCLD) and People First we will build on the Covid-19 experience of providing access to accessible information. This will include using SCLD's website as an accessible information hub and linking into Disability Equality Scotland's Inclusive Communication Hub

Other considerations include ensuring that people are treated with respect and their privacy is maintained when they may need to explain why they need access to accessible and easy read information.

#### **Section 4: Data**

Better data collection and reporting will enable better understanding of the requirements of people with learning disabilities and neurodivergent people throughout their life and build evidence on whether they are able to realise their rights.

It is important that the population of neurodivergent people and people with learning disabilities are visible in topic specific data collections where these are of particular interest, for example, employment data.

#### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

In order to achieve the desired outcomes, organisations often need to link different pieces of data to paint a full picture. However, a barrier to being able to do this is that there needs to be a legal basis for some types of data to be collected, including personal data. The Bill could provide an opportunity for data to be collected in particular circumstances if that would be beneficial to neurodivergent people and people with learning disabilities.

### **Proposal 1: Developing a commission(er) with responsibility for data collation**

Within the section entitled “Accountability”, there is discussion on the possible creation of a new Commission or Commissioner, or adding to the remit and powers of an existing body. If a Commission or Commissioner (or other relevant accountability model) is created, their functions could include responsibilities for collecting and analysing data on neurodivergent people, and people with learning disabilities.

Additionally a body could have powers to make recommendations to other organisations collecting data to disaggregate their data to the level of neurodivergent people, and people with learning disabilities.

There are some other options that would need to be developed further, however, to help us with this, we would like to know your views on the following:

**Proposal 2:** Placing duties on some relevant public bodies to collect data on neurodivergent people and people with learning disabilities where this would be helpful for better understanding of the needs of these groups, their experiences, informing service design and improvement, and to allow for evaluation of measures to improve outcomes for these groups.

**Proposal 3:** Placing duties on some relevant public bodies to provide returns to the Scottish Government regarding local data on people with learning disabilities and neurodivergent people, where this would be helpful for better understanding of the needs of these groups, their experiences, informing service design and improvement, and to allow for evaluation of measures to improve outcomes for these groups.

**Proposal 4:** Consideration of the development of a Scottish version of the Learning Disability Mortality Review (LeDeR) programme. This helps reduce inequalities in care for people with a learning disability. It could reduce the number of people dying sooner than they should.

### **What Do You Think?**

Which of these proposals do you **agree** with (if any), please tell us why?  
**Proposal 1: Developing a commission(er) with responsibility for data collation**

It is recognised that a number of different organisations already have activities with regards to data collection and monitoring for people with learning disability and autistic people. Collaboration and ensuring that there is not duplication is important.

Proposal 1: A commission/er with responsibility for data collation - **The Mental Welfare Commission for Scotland**

The Mental Welfare Commission has a statutory duty to monitor the use of the 2003 Act and the welfare parts of the Adults with Incapacity (Scotland) Act 2000 ('the 2000 Act). The Commission publishes monitoring reports with comment and analysis of trends in the use of the Acts. The reports provide a comprehensive source of information for services, they influence legal reform and identify areas where work is required. We draw attention to some aspects of the monitoring pertaining to Learning Disability.

#### Mental Health Act (MHA) Monitoring report

The rates of detention for people with learning disability and autistic people who do not have an additional mental illness have been highlighted as a concern. From the most recent MHA monitoring report we can see that 1% of Short-Term Detention Certificates in Scotland over 2021/22 were for learning disability alone and 2.1% were for learning disability and mental illness. For Compulsory Treatment Orders 0.8% were for learning disability alone and 2.7% for a dual diagnosis of learning disability and mental illness.

The Commission has reviewed mental health act data for people with autism subject to the mental health act. It is not possible to easily extract this information and it may be helpful to consider how the presence of an autism diagnosis is recorded in future.

It is also unclear how well additional diagnoses are recorded when people with learning disability and autism are subject to the mental health act (including whether someone with a learning disability also has a diagnosis of autism).

When considering the place of learning disability and autism in the mental health act and when people with learning disability and autistic people may be subject to the mental health act without an additional diagnosis of mental illness it would be



valuable to better understand whether co-morbid conditions are adequately considered and monitored.

[MentalHealthAct\\_MonitoringReport\\_2022.pdf \(mwcscot.org.uk\)](#)

### **AWI monitoring report**

The Commission has safeguarding duties in relation to people who are subject to the protection of the Adults with Incapacity 2000 Act. This duty includes monitoring the use of welfare guardianship orders for adults with a mental illness, learning disability, dementia and related conditions, to determine how and for whom the 2000 Act is being used. This helps to inform policy and practice.

From the AWI monitoring report 2022-2023 we know there were a total of 17,849 individuals subject to a guardianship order in Scotland on 31 March 2023 compared to 17,101 in 2022. The most common primary diagnosis was learning disability (46.0%).

[AWI-MonitoringReport\\_2022-23.pdf \(mwcscot.org.uk\)](#)

### **Themed visits**

The MWC carries out national themed visits where we will visit individuals in similar services across the country then report on findings. The Commission has recently completed visits to individuals in specialist services out of NHS Scotland. This includes people with learning disability and autistic people subject to delayed discharge and continues the work undertaken in the No Through Road report (see below).

[OutOfNHSArea-ThemedReport\\_20230907.pdf \(mwcscot.org.uk\)](#)

In 2024 the Commission will continue to undertake focussed visits to Community Learning Disability Teams (CLDT) with the aim of developing a greater understanding of the care and treatment available to people in those services.

### **Proposals 2 & 3 Data Collection and Data Reporting**

Linked with national strategy, health equality, reporting from annual health checks, dynamic support register and peer support panel.

Extend data collection from annual physical health checks to include children and young people recognising the high levels of ill health in this population. Extension could include data relating to those from point of diagnosis to ensure early identification, early intervention regarding physical and mental health, preparation for transition and to examine lifespan mortality rates.

Extend data collection from dynamic support register processes to ensure that information about the care and treatment of young people who are already living away from their home is considered within commissioning processes and in recognition of the fact that we are aware of young people who are ready to move to adult services but remain delayed in adolescent services that no longer meet their needs due to a lack of adequate provision. This in turn leads to increased mental ill health requiring more intensive support in adult services.

Proposal 4 Learning Disability Mortality Review programme development.

The annual health check for people with learning disability in Scotland places a duty on health boards to report on the numbers of people with learning disability who have died in the previous 12 months and the cause of death.

This may be a helpful starting point to the collection of mortality data for people with learning disability and autistic people in Scotland.

The annual health check reporting does not, at this time, include children and this is unhelpful in moving towards an early intervention and prevention approach to physical and mental health care.

Evaluation of data from the annual health checks when it is reported will be important in better understanding the current health needs of people with learning disability and autistic people. Whether a more robust process such as the LeDeR review in England is required may become apparent when such data is available. In addition to consideration as to the effectiveness of such processes in reducing health inequalities.

Less information is available regarding the health of autistic people. Approximately 1 in 15 people in Scotland with learning disability also have autism and would be considered within the annual health check process.

Whether an equivalent LeDeR process is required for autistic people who do not have a learning disability is required could also be considered but it is not clear how such data is currently recorded if at all.

How such data is reported, evaluated and monitored to ensure progression and improved outcomes for people with learning disability and autistic people could be within the remit of a senior government officer/ adviser who has powers relating to data and accountability.

The annual health check process itself is considered in more detail in that section of the consultation.

In the absence of current Scottish data it is worth considering the Learning from Lives and Deaths – people with learning disability and autistic people (LeDeR) 2022 report:

In 2022 there were 3648 unique deaths for people with learning disability. 42% of deaths were considered to be avoidable (22% in the general population) 57% died in a hospital setting

The commonest causes of death were: circulatory diseases - 16.7%; respiratory diseases - 14.6%; neoplasms - 14.5%; nervous system - 13.6%; congenital & chromosomal disorders 13.3%; digestive system – 7%

3.7% of people died of mental disorders (includes dementia and delirium)

This compares with the 5 commonest causes of death in the general population as being dementia (11.4%), ischaemic heart disease (10.3%), respiratory diseases, cerebro-vascular disease and cancer.

Where there were problems with care, the most commonly identified issue was with organisational systems and process.

[Learning from Lives and Deaths - people with a learning disability and autistic people \(LeDeR\) - King's College London \(kcl.ac.uk\)](https://www.kcl.ac.uk/lede/)

The excessive avoidable deaths is stark and suggests that health inequalities remain a priority for any bill in relation to learning disability and autism. This could have a significant positive impact on a great many people.

The different causes of death faced by people with learning disability in comparison to the rest of the population highlight that the learnings from the Health Needs Assessment reports remain relevant. This identified that people with learning disability have high levels of health needs, different health needs and require different approaches to health care than the rest of the population.

LeDeR began to review the deaths of people with autism in their most recent report however the numbers reported in the first year were a fraction of the numbers of learning disability deaths. Thirty four deaths were reviewed. In 11 cases deaths resulted from suicide, misadventure (including non intended drug and alcohol related deaths) and accidental death (including falls).

There is less data available regarding the health needs of autistic people who do not have a learning disability and this should be addressed.

There is a need for collaboration to ensure capacity for analysis of the existing and any new data-sets based on pathways not just episodes.

Which of these proposals do you **not agree** with (if any), please tell us why?

Proposal 1 New Commission/er

This would add to an already cluttered landscape with risk of overlap and duplication of duties. Avoiding duplication of function is a key concern for a Parliamentary committee looking at the Commissioner landscape [Scotland's Commissioner Landscape: A strategic approach - Scottish Parliament - Citizen Space](#)

Is there anything else that we should consider in relation to data?

Extending data collection via DSR and annual health check to include children and young people to better understand health needs in these groups, whether the same health inequalities are present and to ensure that transition from child and adolescent services is well planned and commissioning needs for young people fully understood.

[Data on the lives of people with learning disabilities in Scotland | FAI \(fraserofallander.org\)](#)

“Responsibilities to be clarified in relation to the publication of Learning Disability Statistics Scotland (LDSS) which has not been published since 2019 to ensure that this data is fit for purpose and continues to be published in full, with the added value of now being collected as part of the wider Public Health Scotland (PHS) SOURCE Social Care data collection realised. Make the most of the potential of existing data, particularly the undertaking of more routine linkage of established existing data relating to the lives and experiences of people with learning disabilities. This should be prioritised and outputs made available on a regular basis. The Scottish Government and partners in PHS and the National Health Service (NHS) should actively consider how they could collate relevant data from General Practices (GPs), alongside how data from the new annual health checks will be used to monitor and report on the health of people with learning disabilities. People with lived experience must have the opportunity to understand and contribute to the decision-making process around this, including the bringing together of this data in order to build a national register of people with a learning disability.”

## Section 5: Independent Advocacy

**Independent advocacy** can play a key role in helping people to secure their rights. An independent advocate will help someone's voice be heard. This can help people to make choices about their services and supports. There are

different kinds of independent advocacy and this includes collective advocacy when people are supported to come together to talk about their experiences and challenge discrimination.

## **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

We are looking at how we can improve rights through the availability of independent advocacy through our policies on:

- The creation of a National Care Service (NCS) through the National Care Service (Scotland) Bill (the “NCS Bill”); and,
- Our response to the Scottish Mental Health Law Review.

### **Proposal 1: Strengthen and improve access to existing advocacy provisions**

We want to take time to make sure that there is more consistency around our approach to advocacy and we want to involve people with lived experience in helping us to design this. To do this, we will:

- work with the Scottish Independent Advocacy Alliance, other organisations and people with lived experience to help identify how best to strengthen rights and access to provision; and,
- develop a consistent definition of ‘Independent Advocacy’.

This work will take place across the Scottish Government and we will ensure that it includes specific consideration of the rights of neurodivergent people and people with learning disabilities. How we legislate for advocacy for these groups will depend on the proposed changes in the NCS Bill and to mental health legislation, including whether people with a learning disability or autistic people remain covered by provisions within the 2003 Act.

This means that **we are not currently proposing a broad right in this Bill to independent advocacy for neurodivergent people and people with learning disabilities**. However, we think there are some other things we could explore in the LDAN Bill especially since the right to advocacy under the Mental Health Act only applies the duty to the State Hospital, Health Boards and local authorities (although Health and Social Care Partnerships may in some cases be carrying out this duty) and only applies to a subset of neurodivergent people (as people with a “mental disorder” under the legislation includes people with learning disabilities and autistic people).

Therefore, we could:

- Provide a power in the Bill that allows us to make regulations around the provision of independent advocacy for neurodivergent people and people with learning disabilities whilst further discussions take place about how to improve this.
- Include a provision in the Bill that places a duty on all public bodies to ensure that all neurodivergent people and people with learning disabilities are given information about advocacy and how to appoint their own independent advocate to support them.

**Proposal 2: Improve our Understanding of Independent Advocacy**

We will also in the meantime identify and gather evidence on specific circumstances where a right to independent advocacy could make a difference.

For example, we know that there are some circumstances where additional support could help, as follows:

- Evidence research published by the Scottish Commission for Learning Disabilities suggests that where women with a learning disability have been subject to gender-based violence they struggle to access support due to discrimination and stereotyping. There can be significant barriers to accessing support and to effective support when people are able to come forward. Professionals may not recognise that someone has learning disabilities and if they do they may not have any relevant training in how to support them.
- The Equalities and Human Rights Commission, in its Inquiry report into housing for disabled people in 2018, recommended that local authorities should ensure that people with learning disabilities have access to good-quality, accessible advice and advocacy when discussing housing options and to help them navigate complex systems.

We could consider whether the Bill could provide some specific legal rights to free independent advocacy in these circumstances, as well as others.

**What Do You Think?**

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1: Strengthen and improve access to existing advocacy provisions  
 Advocacy services are invaluable. The Commission supports the proposal to make regulations about the provision of independent advocacy for neurodivergent people

and people with learning disability and the proposal to place a duty on public bodies to provide information about access to independent advocacy.

The capacity of existing advocacy services to undertake such actions is noted as a concern both with regards to available staffing and with regards to the level of specialist expertise that may be required to work with people who have more severe learning disability, significant communication impairments and additional sensory impairments.

Work with existing advocacy services and the involvement of lived experience groups is required.

A range of resources will be required to ensure that any information provided is meaningfully accessible. This relates to Section 3 Inclusive Communication.

There will be small numbers of people who require highly specialist advocacy and the needs of these groups also requires evaluation, for example, how independent advocacy may be provided to an autistic person who is non-verbal, to a person with severe learning disability who is also deaf or when a person is from a minority ethnic group.

Work with lived experience groups may help to prioritise key points in people's lives where support for decision making would be most valuable.

Proposal 2: Improve understanding of independent advocacy

Access to specialist advocacy is likely to be required by specific groups of people. Groups of people with more than one condition which impacts on their care needs and access to services for example concurrent sensory impairment.

Directive and non-directive advocacy (latter where someone has no verbal / other communication).

Wide range of situations where people need additional support to navigate services and where access to accessible information is not sufficient alone.

Access to specialist advocacy in rural populations.

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to independent advocacy?

The provision of accessible information and access to independent advocacy could be supported by a no wrong door or single point of entry to services model which would place a responsibility on the first health or social care contact to ensure that they support the person to make the initial contact with the service that they are seeking.



## **Part 3: Specific Themes**

This part of the consultation sets out specific themes that arose during our scoping work, and through our work with the LEAP.

### **Section 1: Health and Wellbeing**

Neurodivergent people and people with learning disabilities experience poorer health outcomes than the general population, which can be preventable, resulting in below average life expectancies and death caused by preventable conditions.

It is important that people with learning disabilities and neurodivergent people have good health outcomes in order to access their rights and be able to participate fully in life. Poor health creates an additional barrier for neurodivergent people and people with learning disabilities, potentially limiting or impacting their ability to be active in their communities, access employment or maintain relationships.

#### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

The Bill can help to create the right conditions for people with learning disabilities and neurodivergent people to access supports and services successfully when they need them, helping to prevent illness and improving overall health and wellbeing.

#### **Proposal 1: Neurodivergent and Learning Disabilities Strategies**

We are proposing legislative requirements for national and local strategies in future and we could set out what the strategies must include. For example, in relation to health care, we could ask Health Boards, Integration Authorities and Local Authorities to set out in their local strategies how their workforce planning and service planning has taken into account the needs of the neurodivergent and learning disability populations.

#### **Proposal 2: Mandatory training for the health and social care workforce**

We have set out proposals around mandatory training. In England, the UK Government has introduced a new legal requirement for all health and social care services registered with the Care Quality Commission (CQC) to provide

employees with training appropriate to their role on learning disabilities and autism. In England, this is called the Oliver McGowan Training.

We propose to legislate for a similar training requirement for health and social care in Scotland in the LDAN Bill. However, we could take a wider approach so that the mandatory training focusses on learning disabilities and neurodivergence - not just learning disabilities and autism.

### **Proposal 3: Inclusive communications and Accessibility**

We have set out proposals on inclusive communications and this will impact on healthcare. We propose to legislate for neurodivergent people and people with learning disabilities to be able to request access to alternative means of communication where the offered means of communication is not suitable for them. We also propose better access to easy-read versions of public facing communications and documents. This could include a broad duty to make them available on request as well as an automatic duty to provide them in certain circumstances, such as a duty on National Health Service (NHS) Boards and Health and Social Care Partnerships (HSCPs) to require appointment letters to automatically be produced in easy read.

In addition, we also propose legislating for an Accessible Information Standard for Scotland which would be applicable to NHS Scotland organisations.

We also plan to do more work to look at how far existing complaints systems meet the needs of neurodivergent people and people with learning disabilities.

### **Proposal 4: Patient Passports**

We could place a duty on Health Boards, HSCPs and Local Authorities to ensure that a person's "passport" is able to follow them through whichever care pathways they are accessing, such as a hospital or care home admission, and that these passports include important information about their needs and preferences, including how to communicate with them in an accessible way. This could be similar to Advance Statements that can be used by people with mental health conditions, or it could be based on Promoting a More Inclusive Society (PAMIS)'s Digital Passports.

Passports like these help medical professionals to know how best to support people, their preferred treatments or communication styles, and can reduce barriers and frustration when people have to repeatedly restate their needs. There is currently no statutory duty placed on patient passports and, although they are encouraged as best practice, implementation is inconsistent.

## Proposal 5: Annual Health Checks

We are currently rolling out annual health checks for people with learning disabilities across Scotland. A health check will be offered to everyone who is eligible by end March 2024, backed by £2m of funding per year. Given the really good evidence of significantly poorer health outcomes of people with learning disabilities, annual health checks will make a big difference. We propose to include the delivery of annual health checks as a specific legal duty in the Bill.

Autistic people, people with Fetal Alcohol Syndrome Disorder (FASD) and Attention Deficit Hyperactive Disorder (ADHD) also have poorer physical health outcomes and/ or a lower life expectancy than the general population. There are many possible reasons for this gap, including poor professional understanding among health and care staff, which can result in these groups people having signs of illness or their needs overlooked. Without the right understanding, these groups can miss out on adjustments needed for them to engage in medical appointments which can lead to distressing experiences and avoiding seeking advice. We could include a duty in the Bill which, in effect, extends the current annual health checks for people with learning disabilities to autistic people. We could also consider extending this to people with FASD and ADHD. We would want to first gather more evidence of the need for this.

## What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1 Learning Disability Autism & Neurodivergence Strategies

Yes, See Section 1

Proposal 2 Mandatory training for the health and social care workforce

Yes, see Section 2

Training could focus on people with learning disability and autistic people in the first instance with the intent that much of the relevant learning would be of benefit to services working with people with a wide range of conditions where they share similar difficulties when accessing services such as communication impairments, memory problems, need for accessible information etc.

A model of training that recognises different training needs for health and social care services depending on their level of specialism and their area of expertise will be necessary. A competencies model with introductory, foundation and specialist training levels may support this.

Training provided by lived experience groups to ensure that services respect and understand the value of the lives of neurodivergent people and people with learning disability and include them in decision making across their lives.

### Proposal 3 Inclusive Communications and Accessibility

From our work at the Commission, we know that people with learning disability and autistic people are a diverse group who have a very wide range of needs. High functioning individuals who have a good understanding of their rights and are more able to navigate services may well be able to ask for a means of communication that works for them.

This is not likely to be the case for individual with more significant cognitive impairment and particularly not at times of distress or ill health when they may be trying to access services that they have had no contact with before.

It may be beneficial to ensure that public facing staff have some introductory training to recognise and support people with learning disability and autistic people when they are accessing services.

Automatically providing information to people and their carers and families may be of greater benefit in ensuring that people have all the information that they need.

A no wrong door/ single point of entry to services could also place a responsibility on the first contact to support the person to make the initial contact with the service that is considered to be needed.

Where a person has a patient passport this may also support access to services – if the patient passport is available at the right time and contains the correct information.

Links with independent advocacy is also relevant when people are trying to navigate complex health and social care systems. Especially where they may already be facing difficulties and barriers to care.

### Proposal 4 Patient passports

There are a variety of patient passports, all about me documents etc that are used in health and social care.

Consideration is required as to how to ensure that a patient passport is available at the time that it is needed is important.

It is equally important that the passports contain relevant and up to date information. Collaboration between individuals, their families and carers and a variety of health and social care professionals will be needed to ensure that the passport contains person specific information. Regular review and update of passports is vital to ensure that professionals do not make decisions regarding people on information which is no longer correct.

It is possible that the patient passport could be completed in conjunction with the annual health check to ensure that it contains accurate information relating to a person's health given the significant health inequalities.

#### Proposal 5 Annual Health Checks

The slow progress of the implementation of the annual health check model is notable and reflects the significant capacity issues faced in primary care and in community learning disability health and social care teams.

There is evidence that a range of models are being developed across Scotland and the lack of consistent provision of the annual health check could lead to inequality in health care across the country.

In some areas the health check will be provided within primary care, in others by nurse specialists who work within the community learning disability teams or by separate health check teams. Some services are prioritising certain groups of people such as minority ethnic groups. The effectiveness of these different approaches needs evaluation.

Whilst it is very clear that the health inequalities faced by people with learning disability lead to increased morbidity and mortality, it is concerning that the health needs of people with learning disability have been separated from primary and secondary care services. It raises a question as to why people with learning disability cannot see their GP about their physical health in the way that the rest of the population do and take full advantage of the skills and experience of primary care teams and their links with secondary care.

The creation of new and separate services to undertake annual health checks also means that people with learning disability have additional appointments with professionals that they may never have met before. The annual health check is highly sensitive in content and undertaking this with an unknown person may limit the information that is gathered and could be distressing.

An approach where the delivery of annual health checks is led by primary care in collaboration with specialist learning disability teams where necessary would ensure that people with learning disability and autistic people can access the knowledge and skills of primary care, benefit from established links with secondary care supported by specialist learning disability teams.

It is also important to consider, given the known health inequalities and that people with learning disability's access to services can be negatively impacted by organisational systems and processes, how wider primary and secondary health services can continue to develop their knowledge and understanding of the health needs of people with learning disability to support their care and treatment across the course of their life.

The initial annual health check data will be important in beginning to understand the health needs of people with learning disability in Scotland now as well as gather data regarding mortality rates and cause of death.

Evaluation of some of this early data will be needed to consider how services and systems deliver care to this group of people before considering extension of this approach.

It would be helpful that an identified senior government officer/ adviser has oversight of data emerging from the health check and dynamic support register processes, sets priorities for any national strategy and ensures implementation of those strategies. A collaborative approach will be important given the range of health and social care organisations involved.

Involvement of lived experience groups is required to ensure that the annual health check process is delivered in a way that meets the needs of the individuals.

We know that people with learning disability have high levels of health needs, high levels of unmet need, have specific health needs that differ from the rest of the population and different causes of death. The current annual health check would not necessarily be suitable for people with different developmental or neurodivergent populations. Should a similar process be considered for these

groups then research is required to ensure that it identifies their specific health needs and priorities.

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to health and wellbeing?

Recognising the resources that are required to achieve the annual health check process it would be helpful to review any evidence as to effectiveness of such checks when provided less frequently, such as alternate years, if that increases their reach.

How an annual health check might input into a patient passport could be valuable to explore.

The health needs of people with learning disability and autistic people and the inherent value of their lives should also be considered. This could be included in mandatory training with direction from lived experience groups. This would be relevant to primary and secondary care teams when considering an individual's quality of life and their being able to access specialist health services as any other person might. It is also relevant to anticipatory care planning, resuscitation care plans and realistic medicine approaches.

It was also true that there was a significant delay before the increased morbidity and mortality figures for people with learning disability were identified through the pandemic.

Where secondary care services have limited contact with people with learning disability and autistic people (particularly as the links between the annual health check and primary and secondary care is not yet clear) and are supporting them at times of significant ill health it is important that they consult with people, families and carers about the quality of people's lives and the value that people bring, when considering aspects of care such as whether a person should be resuscitated in the event of a major medical event.

Access to Liaison Learning Disability services within secondary care across Scotland is patchy. Liaison Learning Disability Nurses working in general hospitals can support secondary care teams in the care and treatment of people with learning disability and autism. Their presence can bring a wide range of benefits including clear links to

the community learning disability teams, supporting pre-operative assessment, familiarising a person to the hospital setting and helping them to understand what will happen to them in hospital, sharing knowledge about an individual's developmental (including communication and sensory) needs, supporting communication including links to specialist Speech and Language Therapy and accessible information, supporting people when they are distressed and agitated, supporting families and carers, advice about the use of mental health and capacity legislation and provision formal and informal education and training. The provision of such services across Scotland should be evaluated.

## **Section 2: Mental Health and Capacity Law**

Current mental health, capacity and adult support and protection legislation in Scotland can, in certain circumstances, apply to autistic people and people with learning disabilities.

The law uses the term 'mental disorder', as defined within the Mental Health (Care and Treatment) (Scotland) Act 2003 (the "Mental Health Act"). We accept that this term is seen by many as stigmatising and offensive towards people with lived experience. However, it is used in this document to reflect the language of the legislation, where needed.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

The proposed purpose of the LDAN Bill is to better protect, respect and champion the rights of neurodivergent people and people with learning disabilities. The LDAN Bill could, therefore, propose to make changes to mental health and capacity legislation in Scotland as it relates to autistic people and people with learning disabilities. Those changes could be to:

- (1) specifically remove learning disability and autism from the scope of mental health and incapacity legislation; or,
- (2) change "mental disorder" to a term that is not stigmatising or offensive.

However, we are not at this time consulting on any proposals for legislative change in this area. This is not because we do not think it is important but because more work needs to be carried out to consider how we balance the different recommendations of the Rome report and the Scottish Mental Health Law Review (SMHLR).



We know that people with learning disabilities and autistic people have been asking for change in this area for a long time. We therefore need to consider what we can do to address these concerns and what this would mean in practice, including any consequences to the rights and protections the Mental Health Act provides to people with learning disabilities and autistic people who are currently treated under this legislation.

We know that people took time to make their views clear to both the Rome review and the SMHLR. We are not asking for those to be reiterated. We now want to develop options and consider whether there is an evidence-base for potentially making changes, ahead of wider reform. We need to more fully understand the consequences and implications of any changes, including any unintended consequences, to ensure that people with learning disabilities and autistic people still have appropriate rights, protections and support where needed.

For example, if we were to remove learning disability and autism from the current definition of mental disorder, we need to understand what this means for some of the people who are currently receiving care and treatment under the Mental Health Act.

A short-term piece of work is being prioritised as one of the first actions under the Mental Health and Capacity Reform Programme. That work will consider the current definition of mental disorder within the Mental Health Act and the approach to compulsory care and treatment and safeguards. This will include, amongst other aspects, consideration of whether learning disabilities and autism should continue to fall within the definition, along with updating the language of the definition.

The outcome of this work may lead to a change in the law. The LDAN Bill may be an appropriate place to make those changes, however, that will be determined once the work has concluded.

Initial work on this has begun with a scoping workshop held in November this year to help inform the design of the workstream.

## **What Do You Think?**

Do you agree with this approach? Please tell us why?

People with learning disability and autistic people experience high rates of mental ill health with evidence suggesting that at any time 1 in 2 people with learning disability have clinical symptoms of mental illness.

People with learning disability and autistic people can present with very different symptoms when they are experiencing physical and mental ill health and this often

means that diagnosis is delayed or symptoms are attributed to the learning disability or autism alone.

When people with learning disability and autistic people have additional communication and sensory conditions, more severe cognitive impairment and other physical health conditions the process of assessment and diagnosis can take longer. With increasing complexity there is increasing need for specialist learning disability health and social care teams to be involved and/ or ensure specialist assessment, diagnosis and treatment.

Whilst it is important to ensure that people with learning disability and autistic people are not inappropriately admitted and do not stay unnecessarily in hospital, it should not be forgotten that mental ill health is common and that in some cases admission to mental health settings is necessary to ensure that people access specialist assessment, care and treatment.

Admission to hospital may become necessary when it is not possible to undertake that assessment and treatment in the home setting due to risk relating to physical and mental ill health and the safety of the person and/ or others.

With the delays in discharging people from specialist inpatient settings it is evident that people with learning disability and autistic people with acute mental illness who require specialist inpatient care and treatment are sometimes waiting longer to access this treatment. This might mean that they receive their care with significant risk to themselves and others in community setting. It might mean that they are sometimes receiving their care in 'general' mental health settings that do not have the same expertise as a specialist unit. This also means that people can be more unwell by the time that they are admitted to specialist units and this also impacts on their families, carers and support providers.

It is also important to consider that when a person with learning disability or an autistic disorder is admitted to hospital without an additional diagnosis of mental illness this does not mean that mental illness is not present. Admission and a period of assessment may be required to ascertain whether there is an additional mental illness. This is in line with what happens for people who do not have a learning disability or autism admitted to psychiatric setting where a period of assessment is required.

In the majority of cases people admitted to assessment and treatment units are subject to MHA and AWI legislation recognising that even with support they are unable to make decisions about their health and well-being due to a combination of their learning disability, their mental ill health and associated conditions.

Safeguards already exist to protect the rights of this highly vulnerable group of people and how these might be extended or strengthened are considered in Part 4 Accountability where the role of the Mental Welfare Commission for Scotland is discussed.

It is critically important to understand the impact of removing learning disability and autism from the mental health act ahead of any reform and the significant concerns about potential unintended consequences that may result from their removal are valid.

Review of language around mental disorder is important given the concerns of people about stigmatising language and discriminatory treatment.

As discussed above, access to specialist mental health services for people with learning disability continues to be needed. Further consideration of mental health services for autistic people who do not have a learning disability is required as this group will have their own care and treatment needs.

#### Mental Welfare Commission Mental Health Act (MHA) Monitoring 2022

From the most recent MHA monitoring report we can see that 1% of Short Term Detention Certificates in Scotland over 2021-2022 were for learning disability alone and 2.1% were for learning disability and mental illness. For Compulsory Treatment Orders 0.8% were for a learning disability alone and 2.7% for a dual diagnosis of learning disability and mental illness.

[MentalHealthAct\\_MonitoringReport\\_2022.pdf \(mwcscot.org.uk\)](https://www.mwcscot.org.uk/MentalHealthAct_MonitoringReport_2022.pdf)

These figures do not consider when a person with learning disability might also have a diagnosis of autism and more complex clinical needs. It is also likely that in a number of cases there is an additional psychiatric diagnosis that has not been recorded, for example an anxiety or mood disorder.

Whilst it is understood that people with learning disability and autistic people with learning disability are delayed in hospital far longer than other people it is also recognised that this often reflects a lack of appropriate specialist services in the community.

Place of safety figures discussed below show that when autistic people are admitted to hospital that this often results from concerns about their safety and significant risk to themselves or others.

Admission to a psychiatric setting rather than to a community-based service may reflect the level of risk with which the person is presenting and their need for specialist care and treatment. The lack of any alternative community placement will also play a part in the necessity of admission. This is also in keeping with the delays in identifying a service in the community to discharge the person to.

Safeguards within the Mental Health (Care and Treatment)(Scotland)Act:

In addition to a requirement to meet set criteria to allow compulsory detention, the MHA provides additional safeguards when people are subject to compulsory treatment which include:

Independent role of the mental health officer

Statutory review of compulsory orders by responsible medical officer

Review by Mental Health Tribunal Scotland

Right of appeal

Access to independent advocacy

Appointment of a Curator Ad Litem where a person is unable to make decisions even with support for decision making

Independent psychiatric review of psychiatric medications beyond 2 months

Advance statements

Potential to nominate a Named Person

Ability of the listed initiator making an application or an appeal where the person does not have the capacity to do so

Role of MWC in monitoring the use of the MHA

#### Mental Welfare Commission: Autism in the Mental Health Act 2018

At present it is not possible to readily extract equivalent information regarding the use of short-term detention and compulsory treatment order certificates for people with a diagnosis of autism with or without additional mental illness. A previous MWC review of autism in the MHA looked at all new compulsory treatment applications (CTO1s) from a 12-month period spanning 2016 and 2017.

Of a total of 1342 applications, 44 people were identified as being autistic (3%).

In 0.15% of cases the person was subject to compulsory treatment due to autism alone, with no additional diagnosis of learning disability or mental illness.

30% of cases had an additional mental illness and these included schizophrenia/psychosis, anorexia nervosa, anxiety, depression and vascular dementia. In 23% of cases there were diagnoses of learning disability and mental illness in addition to a diagnosis of autism. The types of mental illness that were recorded included bipolar affective disorder, depression, obsessive compulsive disorder, psychosis, anorexia nervosa and anxiety.

Text recognition was required to ascertain whether a diagnosis of autism had been made. That there is no specific option to code autism as a diagnosis at the time of application for an initial compulsory treatment does not readily support data collection regarding the use of the MHA in autistic people.

The research project also reviewed the care needs and treatment plans of the 44 cases that were identified and the following care needs were identified:

- Anxiety and/ or agitation (84%)
- Vulnerable/ at risk of neglect/ needing a place of safety (65%)
- Physical aggression (56%)
- Self harm (35%)
- Communication needs (30%)
- Required structured activities and routine (26%)
- Verbal aggression (21%)
- Damage to property (14%)
- Other behaviours that challenge (9%)
- Sensory needs (7%)
- Sexually inappropriate behaviour (2%)

The treatment that was proposed in these 44 cases included:

- Rehabilitation/ habilitation/ transition (100%)
- Safe environment/ no access to harmful materials (95%)
- Pharmacological interventions (93%)
- Structured activity/ skills development (44%)
- Physical health needs (35%)
- Restraint where necessary (33%)
- Support ADLs (33%)
- Positive Behaviour Support/ equivalent (28%)
- Dietary support (28%)
- Emotion regulation/ support (19%)
- Communication assessment and treatment (14%)

The figures shown here demonstrate that when autistic people are admitted to mental health settings there are often concerns about their safety or the safety of others, that anxiety and agitation are prominent features and that a safe environment and specialist care and treatment were required in the majority of cases.

If learning disability and autism are removed from the MHA this may prevent admission to hospital at such times with significant ongoing risk to the person and their families and carers. Whilst the reported numbers are small, it is a small but

significant group who would not have access to the support, care and treatment they need at the right time for them.

Data reported via dynamic support registers will be valuable in understanding some of the issues regarding the admission of people with learning disability (including autistic people with learning disability) to hospital and why they may then become delayed in hospital. This is considered in Section 3.

The Mental Welfare Commission for Scotland has statutory duties regarding the protection of people who are subject to mental health and capacity legislation. How some of the existing safeguards can be strengthened by extending the work of the Mental Welfare Commission is considered in Part 4 Accountability.

### **Section 3: Social Care**

For those people who need it, social care, social work and community health are vital supports that enable people to live fuller lives connected to their local communities.

People with learning disabilities and neurodivergent people are more likely to present with care and support needs compared to some other groups and those needs may be perceived as more complex by the people providing the services. Without the right support from care practitioners, people are much more likely to need hospital care. This applies in particular to those with complex care needs.

#### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

##### **Proposal 1: Neurodivergent and learning disabilities strategies**

We are proposing legislative requirements for these strategies in future. For local strategies, we could ask Integration Authorities and local authorities to set out how they and organisations they commission will take into account the needs of neurodivergent people and people with learning disabilities in their workforce planning and workforce training, including how they are meeting requirements around inclusive communications and accessibility.

##### **Proposal 2: Mandatory training for the health and social care workforce**

In England, the Health and Care Act 2022 introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission (CQC) to provide employees with training appropriate to their role on autism and learning disabilities – the Oliver McGowan Training.

We propose to legislate for a similar training requirement for health and social care staff in the LDAN Bill. However, we could take a wider neurodivergent approach to the training so that it focusses on neurodivergence and learning disabilities, and not just autism and learning disabilities.

### **Proposal 3: Inclusive communication and Accessibility**

We propose to legislate for neurodivergent people and people with learning disabilities to be able to request access to alternative means of communication where the offered means of communication will not work for them. We also propose better access to easy-read versions of public facing communications and documents made by public authorities. This could include a broad duty to make them available on request and an automatic duty to provide them in certain circumstances, such as: a duty on National Health Service (NHS) Boards and Health and Social Care Partnerships (HSCPs) to require appointment letters to automatically be produced in easy read.

We also plan to do more work to look at how far existing complaints systems meet the needs of neurodivergent people and people with learning disabilities.

### **What Do You Think?**

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1 Learning Disability & Autism Local Strategy

Yes

Led by National Strategy

Linked with local strategies for housing, employment, etc.

Proposal 2 Mandatory Training

See Part 2 Section 2

Proposal 3 Inclusive Communication & Accessibility

See Part 2 Section 3

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to social care?

We draw your attention to the following report:

[FAI-adult-social-care-learning-disabilities-Feb-21.pdf \(fraserofallander.org\)](#)

“Despite positive developments and significant change over the last ten years, our latest report highlights where there are shortcomings in the system. We analysed a wide evidence base and found that:

The closure of long stay hospitals and institutions was driven by consensus from policy makers and civil society, and delivered by means of substantial financial investment to help people transition to community-based support. Any future substantial changes in the way care is delivered should learn lessons from how this was achieved.

Since the financial crisis, there has been a loss in some of the non-statutory support that was so vital for people, particularly with mild to moderate learning disabilities, to live their lives independently. This means the ambitions set out in the Scottish Government’s strategy, *The Keys to Life*, have had little chance of being realised. It is crucial that there is a system in place that allows people to access the support that they need. Self-directed support should have helped achieve this, but we’ve been told that the complexity of the system has arguably made it harder for people with learning disabilities to access what they need. This highlights the issue with assuming that all social care users will benefit in the same way from innovations in how support is delivered.

The transition from childhood services to adult services is a critical time for young people with learning disabilities. There is no question that young people need more support in navigating this time in their lives so that they know what their rights are and how to access the support that can enable them to achieve their ambitions. The Covid-19 pandemic has been detrimental to the support relied upon by people with learning disabilities. Some of this has been the result of restrictions on face to face contact, and given the heightened risks that people with learning disabilities face, in many cases this was unavoidable. However, there can be no doubt about the harm this has had on people and their families. Now there are fears that support will not return post-pandemic at the same level it was before. The opposite needs to be true if people are to recover from the harms created over the past year.”

Social isolation was the most commonly reported worry/negative for adults with learning disabilities, with other frequently reported worries/negatives including: changes to/loss of routine; loss of support, clubs, or services; decreased health, wellbeing, or fitness; and, worries about themselves or other people getting COVID-



19. A large proportion of participants indicated that nothing positive had happened because of COVID-19, but for participants who did report a positive, this most commonly included: digital inclusion; more time spent with important people; improved health; wellbeing, and fitness; and, a slower pace of life.

[The experiences of adults with learning disabilities in the UK during the COVID-19 pandemic: qualitative results from Wave 1 of the Coronavirus and people with learning disabilities study: qualitative results from Wave 1 of the Coronavirus and people with learning disabilities study — Ulster University](#)

[New research on learning disabilities in Scotland | FAI \(fraserofallander.org\)](#)

“Unpaid carers provide significant public value. We surveyed unpaid carers in Scotland and found that, on average, it would have cost the taxpayer £114,000 per year to deliver equivalent care to that provided by each unpaid carer in our sample. However, many that we surveyed told us that they felt undervalued by society and felt then they needed more support.”

## **Section 4: Housing and Independent Living**

Appropriate housing for neurodivergent people and people with learning disabilities is crucial in helping them to live safe and independent lives. Whilst most people live in mainstream housing, for some people accessible or supported housing will be the most appropriate option.

Unsuitable housing can have a negative impact on neurodivergent people, people with learning disabilities, their families and their carers, including impacting on mobility, poorer mental health social isolation and a lack of employment opportunities. Appropriate housing is therefore an essential requirement of independent living.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

The Bill could provide a stronger focus on how public authorities’ duties around housing and independent living can best be met for people with learning disabilities and neurodivergent people. Some or all of the following could be explored further for possible inclusion in the Bill, or other work.

#### **Proposal 1: Advice, advocacy and guidance**

Adequate housing advice, support and advocacy were thought to be necessary to enable neurodivergent people and people with learning disabilities to access their rights to housing and independent living. There is

already an advice service available, Housing Options Scotland, however this is not an independent advocacy service.

Whilst another section of this consultation deals with independent advocacy, this could include consideration of the introduction of specialist advocacy services for housing support.

## **Proposal 2: Neurodivergence and learning disabilities strategies**

Strategies are discussed in the overarching themes section of this consultation where we propose legislative requirements for national and local strategies in future. We could require strategies produced by local authorities to set out how independent living principles are embedded into assessment and allocations policies, to ensure real choice and control.

Local Authorities must currently produce Local Housing Strategies. We could consider whether these must also set out how the needs of neurodivergent people and people with learning disabilities are met, and to evaluate their progress.

With regard to Integration Authorities, we could consider requiring that their neurodivergent and learning disabilities strategies must: set out how housing, care and health services are integrated; describe the supports available to people to help them live independently; and, evaluate progress against this.

## **Proposal 3: Mandatory training for housing professionals**

As set out in the overarching themes section, we have proposed introducing a statutory requirement for learning disabilities and neurodivergence training for professionals who work in health and social care settings. We could consider extending this requirement to housing service professionals.

## **Proposal 4: Data**

We could consider the following in relation to data collection on housing and independent living:

- Relevant public bodies, such as local authorities, to improve the way data is collected and shared, on the requirements of neurodivergent people, and people with learning disabilities, and their housing needs.
- Collection of data on how many people with learning disabilities are considered not to have access to appropriate housing.

## **Proposal 5: Inclusive communications**

We are making proposals to improve communications. We think there is likely to be a need for some documents in relation to housing to be available in easy read formats.

## What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

### Proposal 1 Advice, Advocacy & Guidance

Yes

These approaches may have limited effect until there is housing provision which meets the needs of people who do not have access to appropriate housing and support now and the needs of future generations of people with learning disability and autism.

### Proposal 2 Strategy & Proposal 4 Data

Yes

Ensuring that the correct data is gathered to meet the current and future housing needs of people with learning disability and autistic people in conjunction with clear local housing strategy.

Forward thinking commissioning of services as it is clear that service development can take years and this adds to the delayed discharges and people living in inappropriate settings.

Recognition that service commissioning is not a single process but needs to meet the needs of continuous populations of children and young people as they transition into adulthood and anticipating those needs.

### Proposal 3&5 Inclusive Communications

As stated previously.

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to housing and independent living?

“Housing is a cornerstone of independent living, yet an undersupply of quality accommodation for people with learning disabilities constrains choice and results in

delays. Suitable accommodation is a vital form of support in itself and accounting for this undersupply will require planning in housing strategies.”

[Scotland's adult social care system for people with learning disabilities | FAI \(fraserofallander.org\)](https://www.fraserofallander.org/)

## **Section 5: Complex Care – Coming Home**

We know that some people with learning disabilities who have more complex care needs spend a longer time in hospital than is medically necessary often due to a lack of appropriate community support. This is called delayed discharge. We also know that some people are living away from their home communities and families even though they did not choose to. This is often called living in an inappropriate out-of-area placement.

The Scottish Government knows that this is completely unacceptable and we want to change it. We have been working to improve this for people with learning disabilities and complex care needs and this is often called the *Coming Home* programme.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

#### **Proposal 1**

Dynamic Support Registers are our new way of ensuring we know how many people are in a delayed discharge or inappropriate out of area placement and involve collecting and publishing this data. We want to strengthen the Dynamic Support Registers and the processes around them through the LDAN Bill so that it becomes law for the relevant local public body (Integration Authority, Local Authority, Health Board) to hold these. This would help to ensure that there is visibility for people with learning disabilities and complex care needs on a national level, and that a consistent approach is taken.

Each area would be required to have a Dynamic Support Register, and to report data from it to Public Health Scotland (PHS) for it to be published. It is important to note that personal information about people on Dynamic Support Registers is not published, and none of the data that is published nationally identifies the individuals that it is about.

If we do not make this a law, then Integration Authorities could decide to monitor people in a different way. It could also be more difficult to ensure that sufficient planning and early intervention is being put in place.

## **Proposal 2**

The National Support Panel (“the Panel”) should work with and support the new Dynamic Support Registers and Peer Support Network and we think there are different ways to do this. We want to consider different options, including whether we should make the Panel statutory in the LDAN Bill.

The Coming Home Implementation Report recommended a National Support Panel that could understand and hear from families and individuals about their individual circumstances. One way to do that is to establish a panel that would look at every individual case.

Although we have thought about this, we do not think it would work in practice due to the length of time it would take a panel to consider every case. We would need several panels to make this work and we would need to use our small pool of experts in Scotland to do this. We think this would make the situation worse for people who need quick solutions.

We have set out below the options we think could work under proposal 2.

### **Option A: Legislative Panel Conducting Individual Reviews within Defined Parameters**

This type of Panel would be made up of sector experts and people with legal and clinical knowledge.

This type of Panel would have a function allowing it to conduct investigations into individual cases on a discretionary basis. The Panel could have a list of potential circumstances that may give rise to a review or investigation and where the Panel members might decide that an investigation would provide a good example of what could be done to address complex barriers or issues.

This would mean that not everyone would get an individual review. However, Integration Authorities, Local Authorities and Health Boards would be able to use the findings and learnings from the Panel’s example individual case reviews to improve their practices.

The Panel would be reviewing fewer cases and therefore the demand on the Panel and its members would be reduced to a manageable level.

### **Option B: Legislative Panel Conducting Peer Reviews of Local Processes**

Another option for a legislative Panel would be one that conducts Peer Reviews of Local Processes.

This Panel would consist of a group of experts who could provide checks and balances through a model of peer reviews. It would be made up of a 'bank' of expert members, including people with lived experience, who could be brought in to conduct peer reviews of the work and processes of Health Boards, Local Authorities and Integration Authorities in relation to this population.

This process would involve the Panel going to a local area and reviewing the relevant public bodies' systems and processes in relation to complex care needs, to identify key challenges and issues. The Panel would then provide recommendations or decisions based on the peer review that the Health Board, Local Authority and Integration Authority would have to implement. The Panel would provide follow up support and would monitor progress.

The Panel might review systems and processes that could be of benefit to everyone – things like:

- Commissioning appropriate accommodation and services
- Securing and financing support packages
- Identifying suitable support providers.

This panel would be legislative, so the relevant public bodies (Health Board, Local Authority, Integration Authority) could be required by law to participate and could also be required by law to implement the recommendations made by the Panel.

Although this type of Panel would not be able to review individual cases as part of their role, their reviews would have a significant impact on those individual people and their outcomes.

### **Option C: Non-legislative Panel Conducting Peer Reviews of Local Processes**

A non-legislative National Support Panel Conducting Peer Reviews of Local Processes would work in the same way as the Panel described in Option 2, however it would not be legislative.

Because this Panel would be non-legislative, it could be set up more quickly than a legislative one. However, it would not be the law for Health Boards, Local Authorities or Integration Authorities to participate in peer reviews. The peer reviews would be voluntary, with the option of local areas being able to request a review.

### **What Do You Think?**

- Should there be a statutory duty upon the relevant public body or bodies (Integration Authority, Health Board, Local Authority) to hold a Dynamic Support Register? (Proposal 1)

Yes  No

Please tell us more?

We support the strengthening of the dynamic support register and associated processes.

What local dynamic support register systems look like should be set out in National Strategy to ensure a robust and consistent approach with systems that ensure:

Strong links and between health and social care multi-disciplinary teams, services leads, finance and commissioners.

Clear responsibilities of local health and social care service leads

Data recording and reporting.

Lived experience representation.

Flexible finance arrangements, contingency planning and contingency fund

Provision of crisis and respite services

New and more effective ways of supporting people with learning disability and autistic people who present with distress and associated behaviours via community services such as adult equivalents to family foster placements and supported accommodation and rehabilitation services that are able to manage high levels of distress and associated behaviours that challenge.

Key elements would include:

Local service commissioning targeting gaps in service identified through the work of the DSR RAG processes and meetings and prioritised via national strategy with national oversight towards implementation.

Where there is a lack of progress beyond clearly defined time frames there should be local escalation processes to an independent Regional/Board panel with senior management involvement and oversight including the appointment of an independent chair, lived experience representation and the ability to seek guidance from specialists where there are specific health complexities.

The peer support network could also have a role in providing advice and guidance in such situations.

People, families and carers should also be able to ask for an independent review if they have concerns about a lack of progress or the approach that is being taken.

The Mental Welfare Commission for Scotland can also be contacted for advice by people and professionals through existing mechanisms if there are concerns about the rights and safeguarding of an individual with mental disorder. This is further explored in Part 4 Accountability.

The Mental Welfare Commission has previously published an investigation report on this theme:

**Investigation into the delayed discharge of Ms ST. September 2019**

Ms ST has learning disabilities, cerebral palsy and diabetes and is registered blind. The Commission decided to investigate this case because it felt that Ms ST had experienced a very lengthy delay in an unsuitable environment, and this had impacted on her human rights. Recommendations to Health and Social Care Partnerships included “to put in place governance measures to ensure that assessment and support planning: is carried out in line with national and local guidance; has the rights, will and preferences of the person central to the process; and that where there are significant differences of opinion this is clearly documented and provided to decision-makers.” There were additional recommendations regarding formal dispute mechanisms, case reallocation and mediation and reference to the Scottish Government guidance on discharging adults with incapacity.

Recommendations to Local Authorities included effective prioritisation of MHO referral for people experiencing delayed discharge; respect and support for the MHOs independent role and senior manager oversight. Further reference is made to the Scottish Government guidance on Discharging Adults with Incapacity guidance with respect to proactive case management of private guardianship applications, and an escalation process where required. Additional recommendations were made to the specific HSCP regarding case records standards.

Amber Categories

Reporting is currently focussed on those already in hospital and those at imminent risk of placement breakdown (the ‘red’ group). Local DSR will hold additional information about people who may be at risk of placement breakdown, where it is less imminent, the ‘Amber’ group. The local DSR teams should also consider the needs of people in the ‘amber’ group and this is considered to be a priority area with regards to progressing early intervention and prevention and may be associated with better outcomes. The importance of this group should not be overshadowed by the simultaneous and more acute need to find solutions for people in the ‘Red’ group.



How DSR processes link with transition, local housing and social care strategy etc will require multi service input and priorities for this should be directed by national strategy and as set out in local strategy.

It would be valuable to extend data collection to children and young people to prepare for transition much earlier and ensure that there is adequate time for the commissioning of services where this is required. A similar approach could be taken where children and young people are already in institutional care settings (either within the local area or out of area), for those requiring use of restrictive interventions and for those delayed in adolescent services awaiting a home in the community are considered in the 'Red' group.

Many of the recommendations of the Coming Home processes remain highly relevant:

*"7.2.5 Risk Register Better local monitoring of those at risk of admission, by people who know the person, who can make decisions, and have access to funding may assist in preventing admission, particularly where these people have some flexibility in how they problem-solve at a local level. HSCPs, working with service providers, community health teams and families, should have local risk management strategies in place to identify those who are at risk of placement breakdown leading to hospital admission or out-of-area placement. This could be achieved via a risk register process. This should mean regular reviews and a link in to the development of crisis contingency planning, in order to avoid placement breakdown, and should be effective in providing better anticipatory care planning. Risk of admission should be viewed by HSCPs as a critical event in a person's life, resulting in prioritised care management."*

How local processes anticipate and meet the needs of people with behaviours that challenge, given that this is often a significant factor where people remain delayed in hospital needs considered in parallel with regional and national service development. Key elements of effective services for people with learning disability were identified in the Coming Home work:

*"Throughout the work of this project, an aim was to come to an understanding of what good support for people with learning disabilities and complex needs should look like. A number of key elements were identified: • Person-centred approaches • Environments which support communication • Active support and full lives • Positive behavioural support • Suitable accommodation • Skilled and motivated staff • Good management and practice leadership "*

- Which of the options for the National Support Panel (Proposal 2) do you think has the most benefits?
  - Option A
  - Option B
  - Option C

Please tell us more?

It is not clear that a national oversight panel is going to result in better outcomes for people where there are clearly functioning local processes and some of the common themes relate to a wider social care crisis and a lack of alternative community and national service developments.

The Mental Welfare Commission for Scotland via phone line, casework and visits is aware of some of the common themes that are arising which lead to people with learning disability and autistic people being admitted to hospital and being delayed in hospital. Lack of appropriate housing in the right locations, lack of capacity of social care providers to take on additional care packages and in some cases breakdown of existing care packages due to difficulties in recruiting and retaining staff, people delayed in hospital who require highly specialist care that may previously have been provided via independent hospital care and lack of additional capacity in those services, high levels of acuity in inpatient settings.

In many cases multi-disciplinary health and social care teams have worked hard to identify appropriate community care packages for individuals but there has been a lack of progress due to some of the issues noted above.

An alternative approach may be to have a senior LD&A adviser/ director within Scottish Government who has oversight of the priorities, strategy and data intended within this Bill and their implementation and can collate issues arising from the Regional/Board review about areas of unmet need.

Collaboration between many services is required with a whole system approach.

Coming Home recommendations remain highly relevant to local service delivery and regional and national planning and in particular:

- development of crisis services
- flexible support services
- co-production commissioning
- commissioning for the future
- skilling up commissioners and care inspectors
- person centred care

- behavioural support expertise
- housing solutions
- regional models (see below)
- workforce development regarding positive behaviour support.

[Coming home: complex care needs and out of area placements 2018 - gov.scot \(www.gov.scot\)](http://www.gov.scot)

Coming Home also identified that behaviours that challenge are often a key factor when people's support services breakdown and they are delayed in hospital.

[Learning disabilities and behaviour that challenges: service design and delivery \(nice.org.uk\)](http://nice.org.uk)

The creation of an additional National Support Panel is likely to be resource intensive and it is not clear how effective this approach would be. Data from CETR & ICETR processes in England showed very slow progress in the outcomes of people who were subject to long term segregation and people delayed in hospital.

[Thematic Review of the Independent Care \(Education\) and Treatment Reviews - GOV.UK \(www.gov.uk\)](http://www.gov.uk)

The peer support panel is already in the process of being established and will be valuable in services sharing knowledge about housing solutions for people who remain delayed and considering local and regional service planning.

### Regional & National Models

In some cases there are no local services that can provide more specialist care and treatment. Whilst the numbers may be small the cost of providing this care can be high due to the level of expertise required. There is value in regional models being developed. This may allow some people to return from out with Scotland in addition to preventing people from having their care needs met far from home.

It is clear that many out of area services are also working at full capacity and that some out of area services provide less than desirable standard of care as they also struggle to recruit and retain staff.

These issues can lead to people with learning disability and autistic people being delayed in hospital settings where their care needs cannot be met and at the same time reduces the ability of those services to provide the care and treatment as intended.

Specific gaps in service include female low secure provision, specialist autism services, specialist services for people with learning disability and autism who have severe behaviours that challenge that would not have their needs met within forensic settings, services for people with dual disability with learning disability and personality disorder who may require more specialist care and treatment than can be provided by either learning disability or personality disorder services alone given the very different approaches to care.

When people are delayed in hospital as there are no national services which provide this highly specialist care and treatment this prevents assessment and treatment units from undertaking their core clinical activities as noted above but also leads to increasing acuity both in inpatient settings and in the community.

#### MWC Safeguarding role

The Mental Welfare Commission for Scotland has oversight of people delayed in hospital and there are mechanisms in place to notify the Commission where there are concerns about the care and treatment of a person subject to MHA and AWI. The Commission can review and investigate the care and treatment of a person in a mental health setting where there are considered to be deficiencies in care and treatment. MWC has undertaken themed visits to people out of area, people with autism in mental health settings etc.

These safeguards, and how the role of the Commission might be extended are considered in Part 4 Accountability. We would be open to considering how we could collaborate with any mechanism to build a systemic picture of need.

#### Are there any other options that you think we should consider?

The Scottish Mental Health Law review recommendation in relation to the role of the Mental Welfare Commission:

The Mental Welfare Commission and advocacy groups should develop a participatory referral process to escalate human rights issues that remain unresolved and unaddressed by services to the Mental Welfare Commission to investigate and, if appropriate, initiate legal action.

How this may link with Dynamic Support Register processes and in particular lack of progression towards discharge for people considered through those processes as an additional oversight option is worth consideration.

The Scottish Mental Health Law Review recommendation regarding conditions of excessive security:

“Right to appeal against being subjected to unjustified restrictions akin to excessive security”.

The potential effectiveness of this approach to people with learning disability who remain delayed in hospital settings whilst subject to the Mental Health Act is worth consideration given the effectiveness of this approach in development of forensic services.

National strategy regarding specialist health and social care environments

[Capable Environments | bild](#)

## **Section 6: Relationships**

Children, young people and adults that have a learning disability or are neurodivergent have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should be able to develop and maintain relationships and get the support they need. However there are a range of barriers that prevent some neurodivergent people, and people with learning disabilities, from having healthy and fulfilling relationships. This often causes loneliness, social isolation, poor mental health, and trauma.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

#### **Proposal 1: Access to Independent Advocacy**

Another section of this consultation discusses independent advocacy. We would like views on any specific circumstances where a right to independent advocacy could make a difference. With regards to this section on relationships, this could include:

- (a) where a parent with learning disabilities is at risk of their child being taken into care; and,
- (b) where a neurodivergent person or person with learning disabilities have disclosed gender-based violence or abuse. This would aim to enable them access to justice and support (as recommended in Unequal Unheard).

#### **Proposal 2: Data**

The overarching section of this consultation sets out some broad proposals on data. With regards to relationships, we could consider data collection on the following:

- (a) Data collection and reporting on gender-based violence affecting women with learning disabilities (as recommended in Unequal Unheard).
- (b) Data collection and reporting on the number of parents with learning disabilities in Scotland, including where their children have been removed from their care. This acknowledges that there is currently a lack of knowledge of this population which may impact on the availability and range of services provided.

### **Proposal 3: Inclusive communications**

We have made some proposals on inclusive communications, and we have asked for views on particular situations where a strengthened right to and focus on inclusive communications would have an impact. With regards to relationships, we could explore the following:

- (a) Where a person with learning disabilities is at risk of having their child removed from their care. This could include information automatically being provided in easy-read, and support provided by professionals who have specialist training in learning disabilities.
- (b) Where a neurodivergent person, or person with learning disabilities, has disclosed gender-based violence or abuse and is interacting with the justice system. This could include information automatically being provided in easy-read, and support provided by professionals who have specialist training in learning disabilities.

### **Proposal 4: National and Local Strategies**

We have set out a proposal for national and local strategies. As part of this, we could explore whether those strategies should include the following with regard to relationships:

- (a) Local authorities to set out how a multi-disciplinary team and Whole Family Approach is being implemented to proactively support neurodivergent parents and parents with learning disabilities, including reporting on and evaluating this approach.
- (b) Police Scotland to set out how people with learning disabilities are provided specialist support to report crimes, including gender-based violence and abuse.

- (c) Local authorities or Education authorities to set out how Relationships, Sexual Health and Parenthood (RSHP) education is provided to all Additional Support Needs learners.
- (d) Local authorities to set out how they provide services to neurodivergent people and people with learning disabilities to enable them to be active and involved in their communities and meeting other people, rather than being isolated at home as is often the case. This could include evaluating the impact of these services.

### **Proposal 5: Accountability**

Another section of the consultation sets out options for increased accountability. This includes proposals for a new Commission/er specifically for neurodivergent people and people with learning disabilities, as well as considering changes to the power and remit of existing Commissions or Commissioners.

If a new or existing body had powers of investigation they may be able to investigate ongoing and historic cases of child removal from parents with learning disabilities, based on their disability.

### **What Do You Think?**

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1 Access to Independent Advocacy

- a) Yes
- b) Yes

Clear direction as to how this role differs from that of Appropriate Adult in justice settings and ability for both to be in place.

Proposal 2 Data

Proposal 3 Inclusive communications

Proposal 4

Local strategies with national strategy and guidance  
 Co-produced by people with lived experience  
 Linking with housing, social care, education, employment outcomes/ intentions across this Bill  
 Social enterprise and funding for this  
 A culture shift in employment

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to relationships?

EHRC article 8 on right to family life is important here alongside UNCRC article 12 on right of the young person to be heard; links with access to technology and digital safety; links with approach in education and what may need to be adapted.

Possibility that lived experience groups could consider what may be required in collaboration with relevant public bodies.

As noted previously, social isolation was the most commonly reported worry/negative for adults with learning disabilities, with other frequently reported worries/negatives including: changes to/loss of routine; loss of support, clubs, or services; decreased health, wellbeing, or fitness; and, worries about themselves or other people getting COVID-19. A large proportion of participants indicated that nothing positive had happened because of COVID-19, but for participants who did report a positive, this most commonly included: digital inclusion; more time spent with important people; improved health; wellbeing, and fitness; and, a slower pace of life.

[The experiences of adults with learning disabilities in the UK during the COVID-19 pandemic: qualitative results from Wave 1 of the Coronavirus and people with learning disabilities study: qualitative results from Wave 1 of the Coronavirus and people with learning disabilities study — Ulster University](#)

National Value of community organisations such as get2gether addressing social isolation, relationships and sexual health for people with learning disabilities.

[Learning disabilities, the third sector and relationships | FAI \(fraserofallander.org\)](#)

[Researching belonging with people with learning disabilities: Self-building active community lives in the context of personalisation - Kaley - 2022 - British Journal of Learning Disabilities - Wiley Online Library](#)

Research on Belonging

1. Belonging means being welcome and accepted in everyday places, at all times of day. For the participants in the study, belonging was about feeling welcome and accepted in everyday places, including favourite shops, local sports centres and at church

2. Being part of a supportive network

For the people with learning disabilities who took part in our study, belonging was about having opportunities to make new friends and engage in social activities.

However, some participants spoke of needing to build up their skills and confidence to meet and spend time with new people. Some people lacked practical skills to



keep in contact with the people they were friendly with, including competence in independent travel and in using an online social network like Facebook. Local friendship and self-advocacy groups were often a lifeline for people, because they provided them with opportunities to make and meet friends.

### 3. Having the right choice and information

In order to lead active lives in the community, people need to know what is going on in their community and the support that is available to them. However, participants' awareness and capacity to find out about the support available and how to access it was hugely variable. Because we were speaking to people who were already engaged in organisations and activities, many participants had learned how to make contact, to keep in touch, and to arrange joint activities. They used skills in texting, using Facebook or WhatsApp, and local travel skills.

[Adults with learning disabilities need support to find love - NIHR Evidence](#)

## Section 7: Access to Technology

Over recent years digital access has become increasingly important to the way we live our lives. It is important to stay connected with family, friends and our communities, as well as being able to access learning and employment opportunities online. Digital inclusion therefore plays a key role in a person's independence. The pandemic made the importance of digital access even more critical, due to many services moving online.

There are many people with learning disabilities who have difficulties accessing digital devices or using digital services and are at risk of being digitally excluded.

There is a need for security, awareness and training in terms of how to use technology and how to use technology safely.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

We have made proposals for inclusive communications and we would expect this to have a positive impact on increased digital access.

**Proposal 1** - We could also consider how to ensure that training is available to people with learning disabilities in digital skills and online safety.

**Proposal 2** - We could gather clear data on the number of people with learning disabilities and neurodivergent people accessing and using technology.

**Proposal 3** - We could make more support available to directly help people with learning disabilities and neurodivergent people access and use technology.

### What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1 Training  
Proposal 2 Data  
Proposal 3 Support

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to access to technology?

#### “Our right to be techy” report SCLD

Recommendation 1: The Scottish Government should provide funding for learning disability digital inclusion coordinators across Scotland. Their role will be to bring together networks dedicated to finding person-centred solutions to digital exclusion and promoting digital technology and participation for people with learning disabilities.

Recommendation 2: The Scottish Government should provide funding for a learning disability lived experience board focused on digital health and social care services and technologies. The Board would provide expertise at every stage of the design and delivery of digital services and solutions that will impact on them.

Recommendation 3: The Scottish Government should support a co-produced learning disability pathfinder project utilising personal data stores to empower people to interact with health and social care services. This pathfinder must include experts by experience, organisations with experience of co-producing such initiatives with people with learning disabilities and be supported by an organisation with expertise in health and social care innovation.

Recommendation 4: The Scottish Government, Public Health Scotland and NHS Boards must ensure a joint approach, with adequate resources, to learning disability data improvement. This will support fair and equitable health and social care

outcomes and lay the groundwork for success in the Scottish Government's strategic priorities across digital health and social care

Conclusion: For any change to be truly transformative, wholesale cultural change is needed. The health and social care sector, and society in general, need to see people with learning disabilities as more than service users. It is imperative we spark a cultural change whereby stakeholders are committed to encourage people with learning disabilities to explore and independently use technology, with appropriate measures in place to ensure people can make informed choices about its use. As the transition towards a digital society continues apace, now is the time to make sure that no one, including people with learning disabilities, is left behind.

[07160-Digital-Transformation-Project-report.pdf \(sclld.org.uk\)](https://www.sclld.org.uk/07160-Digital-Transformation-Project-report.pdf)

## Section 8: Employment

Employment can help people to feel valued and contribute to more independent living. While employment should not be seen as the only option to be a valued member of society, opportunities and choices to work are important for everyone.

The Scottish Government is focused on supporting those furthest from the labour market to progress towards, enter, and sustain employment. We are committed to high quality, fair and inclusive work and employability support. However, we know that many neurodivergent people and people with learning disabilities continue to face barriers to employment.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

Disabled people face some of the most persistent labour market barriers, which is why we have committed to at least halve the disability employment gap by 2038. We agree that more needs to be done to support people with learning disabilities and neurodivergent people to access fair and sustainable employment, particularly in light of the available data which suggests these groups achieve some of the poorest labour market outcomes, even compared to wider disability groups.

**However, given the work that is currently ongoing, and our limitations on changing the law in this area, we are not currently proposing any legislative changes.** Instead, we intend to explore the following in order to promote and encouraging more inclusive approaches:

- Under our Fair Work First approach, the recipients of public sector grants and contracts can be challenged in new ways to work towards meeting the Fair Work First principles. This includes taking action to create a more diverse and inclusive workplace. We can highlight to employers that it is best practice to ensure they undertake disability equality training, including more specialist training for line managers on individual impairments, such as neurodivergence and learning disabilities, where this would enable appropriate support and reasonable adjustments to be provided to staff.
- Training for job coaches on neurodivergence and learning disabilities in the workplace: we are taking forward the Review of Supported Employment within Scotland (2021), which recommended that work continues to support the professionalisation of the supported employment workforce, including ensuring it is well equipped to provide appropriate support to people with learning disabilities and neurodivergent people.
- We will review the language within impairment level (employability) data that the Scottish Government collects on employability to ensure it is consistent with the language individuals and professionals use.

## What Do You Think?

Do you agree with this approach? Please tell us why?

[Learning disabilities and Scotland's labour market | FAI \(fraserofallander.org\)](https://www.fraserofallander.org/)

“Very few people with learning disabilities in Scotland are in paid work despite many being able to work and wanting to do so.

Many people living with a learning disability tell us that having a career would unlock greater choice and control over how they live their lives. Whilst volunteering opportunities are easier to find, this is not the same as having a paid job. Ensuring that more people with a learning disability can access paid work would be a step towards building a more inclusive economy and meeting the Scottish Government's targets over closing the disability employment gap.

Available evidence shows that employment rates for people with learning disabilities have not improved over the past decade, despite record employment figures being reached for the wider population in the period before the pandemic. There are clearly barriers that need to be addressed if the economic recovery from the pandemic is to be inclusive of people with learning disabilities”.

## Community & Social Enterprises

Value in people being able to engage in meaningful vocational and employment activities in the community.

Concern that there has been a decrease in these opportunities post pandemic and as services have lost funding.

e.g. Acorns to trees [Our vision - Acorns to Trees \(acorns2trees.com\)](https://www.acorns2trees.com)

e.g. The Usual Place [Social enterprises and learning disabilities | FAI \(fraserofallander.org\)](https://www.fraserofallander.org)

### [Inclusive employment and the role of social enterprises | FAI \(fraserofallander.org\)](https://www.fraserofallander.org)

“Scottish Commission for People with Learning Disabilities Data 2019 showed that only 4% of adults with a learning disability known to local authorities are in employment, albeit with a high non-response rate. “There are a few jobs for those considered to be ‘high functioning’ but for someone who can only engage for short periods, is non-verbal, who can’t read or understand numbers, whose hand function is severely limited or who needs to move around or talk constantly whilst working, most employers would consider them unemployable.”

“Some of these changes aren’t easy because they require a shift in the way we view work and employment. To include everyone we need employers, professionals and young people to believe they can do it, and want it. We need to be more open to seeing people’s gifts and how they can use them to contribute. We need to stop obsessing over productivity and start measuring things like wellbeing and community too; a few of our team may label 20 candles during a shift, others 60, some bring joy to our workshop which we value more than how much work they do. We need to start being flexible in workplaces; some of our team members work for a full 3 ½ hour shift, some manage 30 minutes. Some need adapted equipment. Many need more than an accessible toilet. Changing Place toilets provide equipment including a hoist and adjustable height changing bench for those who can’t weight-bear or use a toilet. Without a Changing Place we are essentially telling staff that they can’t go to the toilet or be changed whilst they are at work, something non-disabled employees would find unacceptable.”

### [Scotland’s employment landscape for people with learning disabilities | FAI \(fraserofallander.org\)](https://www.fraserofallander.org)

“Here is a summary of our findings:

Employment outcomes for people with learning disabilities are poor and there is no evidence of progress being made.

Employment is not a viable option for everyone with a learning disability, and it is important to recognise that this does not preclude people from leading fulfilling lives. Success does not mean everyone with a learning disability working – it means everyone who can and wants to work having the support and opportunities that enables them to do so.

A lack of disaggregated data means that there is no reliable labour market information about people with a learning disability in Scotland.

There is data on the pan-disabled employment rate. The Scottish Government is unlikely to meet its flagship ambition to halve the disability employment gap without improving opportunities for people with a learning disability.

There is evidence of what works. Case studies presented in this report show that success is possible with the right support in place.

The key challenge is replicating success at scale.

Meaningful progress cannot be made by government alone. It requires all stakeholders, including employers, to take active steps towards more inclusive working environments.

This presents an opportunity for government and employers to invest in the support that will unlock the potential of people with a learning disability.”

[2020-09-25-Scotlands-Invisible-People.pdf \(fraserofallander.org\)](#)

[Invisible-No-More.pdf \(fraserofallander.org\)](#)

“The Scottish Government should carry out an audit of the current employability support schemes on offer in each part of Scotland for people with learning disabilities, and the routes that people come through to access them. This will ensure a shared understanding across Scotland so that new localised schemes are aware of what they have to build on, can ensure good practice is not lost, and gaps in provision are identified. Robust monitoring and evaluation of outcomes for people with learning disabilities is crucial, including follow-up after 12 months to measure sustained outcomes.”

## **Section 9: Social Security**

Social security is a human right and is essential to the realisation of other human rights. None of us know when we might need it. It is a shared investment to help build a fairer society, together. Social security is key for disabled people, including neurodivergent people and people with learning disabilities, to gain independence from families, boost their social participation and support their ability to live with dignity. It can enhance the productivity, employability and economic development of disabled people. And, ultimately,

help to tackle inequalities and allow every person in Scotland to live with dignity, fairness and respect.

We know that neurodivergent people and people with learning disabilities are less likely to be in employment and are therefore more likely to need social security support. For those who are in employment, we know that they may also need social security support if they are unable to work full time, or to help with the additional costs of being disabled.

Neurodivergent children and young people, and children and young people with learning disabilities, and their families, may also need support with the additional costs of being disabled.

## **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

### **Proposal 1 National and Local Strategies**

Requiring Social Security Scotland to report on, and evaluate, how its inclusive communication strategies have taken into consideration the needs of people with learning disabilities and neurodivergent people.

### **Proposal 2: Mandatory training for social security staff**

We have set out proposals for mandatory training for health and social care staff and we invite views on whether there are other public sector areas this should extend to.

With regard to Social Security Scotland, we are aware that there is likely to be a significant proportion of people with learning disabilities and neurodivergent people who are eligible for social security, given the employment rates. We could therefore explore whether there is a need for training on learning disabilities and neurodivergence to be a statutory requirement for some Social Security Scotland staff.

### **Proposal 3: Data collection**

We have set out broad proposals on data in the overarching themes section. To better understand neurodivergent and learning disabilities groups and their needs, including how many people are accessing social security benefits, current data reporting could be disaggregated further. For example, current data reporting on Adult Disability Payment (ADP) in Scotland has a category for “autism and other developmental disorders” but does not report on learning disabilities, Attention Deficit Hyperactive Disorder (ADHD), and Fetal Alcohol Spectrum Disorder (FASD) or other conditions separately.

## What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

Proposal 1 Strategy

Proposal 2 Mandatory Training

Proposal 3 Data

Reasonable adjustments to people with learning disability and autistic people accessing social security services.

Accessible information.

Access to independent information.

Support to navigate social security system.

Support in employment processes.

Leadership of public bodies in opportunities for employment.

Understanding of diverse range of skills and abilities and culture shift regarding value in the workplace.

Meaningful inclusion.

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to social security?

[Understanding Social Security in Scotland: Working age disability and carer benefits | FAI \(fraserofallander.org\)](#)

Many disabled groups have argued that the process of assessing a person's entitlement for PIP causes undue stress and anxiety for disabled people. In 2017 the Scottish Commission for People with Learning Disabilities (SCLD) consulted about the future of social security in Scotland and found the PIP assessment process to be "*embarrassing and degrading*" and that assessments "*can make people feel vulnerable*"

The SCLD report referenced above also found concern around a "*difficult and complex ... application process*" and "*written communication which is complicated, difficult to understand and sometimes does not make sense*". Social Security Scotland have committed to "*embed inclusive communication in everything we do, so that all materials are accessible*".



## **Section 10: Justice**

Although there is a lack of robust data, there are indications that people with learning disabilities and neurodivergent people may be over-represented in the criminal justice system and that their needs can be unidentified and unmet. This can be because of inaccessible information, lack of knowledge and lack of a reliable method of identifying people with vulnerabilities.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

There are many developments happening across the civil and criminal justice system that have the potential to be very positive for neurodivergent people and people with learning disabilities. Some of those changes are broad and not specifically adapted for neurodivergence and learning disabilities but trauma focused work is a key theme that can be built upon for these groups.

We think that there is merit in exploring the extent to which the Bill could seek to improve the position for a neurodivergent person or person with learning disabilities interacting with the justice system in the following ways.

#### **Proposal 1: Strategies and a co-ordinated approach**

We could consider bringing together a single national strategy that deals with neurodivergence and learning disabilities in the civil and criminal justice systems. There are many complex interactions between different parts of the justice system that would benefit from this approach and allow a clear set of priorities to be developed reflecting the other proposals below.

#### **Proposal 2: Data and the identification of neurodivergent people and people with learning disabilities in the justice system**

It is a critical requirement to ensure that neurodivergent individuals and people with learning disabilities and their needs can be appropriately identified at key points of contact with the justice system. This is to ensure that:

- The right kind of communication is used and it is adapted for neurodivergent people and people with learning disabilities;
- Any additional impact of a situation, for example admittance to custody is understood and appropriate adjustments made such as to the physical custody environment;
- Additional supports are provided, such as an Appropriate Adult in criminal justice and access to independent advocacy;

- Appropriate information is fed into key decision points in the justice system to help provide more accurate future data.

At present the onus in the criminal justice system is often on individual police officers to recognise and flag up any additional needs. We want to consider how best to ensure that neurodivergence and learning disabilities are better identified at relevant points and by relevant staff.

The Bill could potentially place a duty on public bodies such as the Police, Crown Office and Procurator Fiscal Service (COPFS), and the Scottish Prison Service to seek to identify neurodivergence and learning disabilities when people are coming into contact with the criminal justice system. This could apply at key points such as:

- When a victim or witness comes forward
- When someone is arrested and brought into custody
- When someone is sentenced
- When someone is admitted to prison to begin a sentence

This is not about diagnosis - it is about identifying the need for support.

It may also be possible to investigate whether a common screening tool across criminal justice agencies could help.

### **Proposal 3: inclusive communication**

Inclusive communication is critical for neurodivergent people and people with learning disabilities and we have set out broad proposals around this in the overarching themes. Those in contact with the criminal and civil justice systems need to be able to fully understand the information they are being given whether they are a victim, witness, party or potential offender. If information is not accessible this can result in people being either unaware of their rights or unaware that they are at risk of breaching standard or special bail conditions. The approach we have set out earlier in this consultation on inclusive communications proposes:

- Better access to easy-read versions of public facing communications and documents made by public authorities. This could include a broad duty to make them available on request and an automatic duty to provide them in certain circumstances. For example, a duty on the Police, the Scottish Courts and Tribunal Service and the Scottish Prison Service to provide information to people accused or convicted of a crime in an accessible way, including standard bail conditions.

- Provide for neurodivergent people and people with learning disabilities to request access to alternative means of communication where the offered means of communication will not work for them. This could mean being able to ask for an online meeting rather than face to face or a telephone call instead of a letter.

#### **Proposal 4: Mandatory Training**

Proposals in relation to mandatory training are set out in the overarching themes section. We propose that the Bill provides for training on neurodivergence and learning disabilities to become mandatory for health and social care staff, and we are seeking views on whether this should be extended to other public bodies.

We could therefore consider extending the requirement for mandatory training to police, prison, COPFS and relevant courts and tribunals staff. We think that mandatory training for staff in the civil and criminal justice systems is a key element to support better identification of needs, better support and improved communications. We know that not all staff will need this but public facing staff would, and we could consider how to define this in the Bill for new and existing staff.

#### **Proposal 5: Advocacy**

We have set out our proposals on advocacy in the overarching themes section. There is currently work going on across the Scottish Government to consider a consistent approach to advocacy and this includes neurodivergent people and people with learning disabilities. We do not want to take anything forward separately on advocacy that is not informed by this work. If necessary, and if this work is not concluded, we could consider the Bill conferring a power that would enable the Scottish Ministers to make any necessary regulations on independent advocacy for neurodivergent people and people with learning disabilities, should this be required.

In addition, mandatory training could include information about the role and availability of advocacy in the civil and criminal justice systems as well as information about the Appropriate Adults scheme.

#### **Proposal 6: Diversion from Prosecution (DfP)**

As with others, neurodivergent people and people with learning disabilities may benefit from the use of DfP where they are alleged to have committed offences. Better identification within the justice system and training for staff to understand how to do this could help. A requirement to identify needs should

allow better information to be provided by the Police to COPFS in the Standard Prosecution Report (SPR). The SPR is the basis on which COPFS can make a decision about DfP. This will also help local authorities when they complete their DfP assessment as they would need to take this into account.

Training and awareness raising provided to professionals working in COPFS on neurodivergence and learning disabilities, how it impacts on people's lives, and how it can have an influence on offending behaviour could help with increasing consistency of decisions around DfP for these groups. This training could include the role of support in reducing the likelihood of re-offending.

## What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

In particular we agree with:

Proposal 3. Inclusive communication

Proposal 4. Mandatory training

Mandatory training which increases the knowledge and understanding of justice services in meeting the needs of people with learning disability and autistic people is supported in principle.

Any such training may need to be adapted as people with learning disability and autistic people who are in justice systems will have different and specific needs in addition to sharing some common issues in how they understand and communicate.

Adaptations to training may require a greater focus on possibility of foetal alcohol syndrome, impact of ADHD and co-morbid conditions including alcohol and substance misuse.

Proposal 5. Advocacy

This Bill could ensure that independent advocacy is provided to people in the justice system who need support for decision making at key times in criminal proceedings.

Proposal 6. DfP

Training will be required to assist with understanding of cause and effect.

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to justice?

How a patient passport might link with better identification of a person with, for example, a learning disability or an autistic person.

## **Section 11: Restraint and Seclusion**

We know that neurodivergent children and young people and those with learning disabilities can have negative experiences at school where restraint or seclusion is used in response to distressed behaviour.

We know that adults in certain settings, including hospital or care settings, may also have negative experiences as a result of restraint or seclusion being used inappropriately.

It is not acceptable for neurodivergent people and people with learning disabilities, or anyone else, to be subject to the misuse of restraint, seclusion or other restrictive practices. This can lead to increased and unnecessary distress and trauma.

### **What can we do about it?**

We have committed to exploring options for legislation in this area that would apply equally to all schools (education authority, independent and grant-aided). This includes the option of statutory guidance.

However, we do not think that the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill would be the right place to do this because it would need to apply to all children and young people, and not just neurodivergent children and young people and children and young people with learning disabilities.

### **What Do You Think?**

Do you agree with this approach? Please tell us why?

Recent review of the use of seclusion and long-term segregation by the Mental Welfare Commission found that these highly restrictive practices are used in Scotland with little governance or monitoring. This results, in part, from a lack of clear

definition within legislation and that there is no duty on services to monitor or report on the use of such interventions.

“We know that people with developmental disabilities are more likely to be subject to these special situations. Where people have significant impairments in their cognitive function and communication skills oftentimes there will be a proxy decision maker in place. Any decision making must place the person and their specific needs at the centre of any care planning and engagement with people with lived experiences and specialist advocacy is essential in achieving this.”

Restrictive or coercive practice is one area of focus of the SMHLR and it will be valuable to see progress there.

In the interim this Bill could provide greater scrutiny of the use of such restrictive practices as seclusion and long-term segregation.

It could place a duty on public bodies to monitor and report on the use of such restrictive interventions.

There could also be a requirement that the Mental Welfare Commission for Scotland is notified when a person with learning disability or an autistic person is secluded or made subject to long term segregation when subject to the MHA or AWI.

Local services could be required to have local seclusion and long-term segregation policies which includes people with learning disability and autistic people.

Local services could also be required to ensure that the individuals have access to independent advocacy for anyone subject to such restrictions.

Clearer monitoring, reporting and oversight of the use of these restrictive practices recognising that there is a small group of people who are unable to make decisions without support and who may not be able to safeguard their own health and well-being.

The Mental Welfare Commission for Scotland Use of Seclusion good practice guidance will support local services in best practice.

[Seclusion GoodPracticeGuide 20191010.pdf \(mwscot.org.uk\)](https://www.mwscot.org.uk/Seclusion_GoodPracticeGuide_20191010.pdf)

British Institute of Learning Disability Capable environments  
Healthy environments which are flexible and responsive and do not increase distress and trauma

## **Section 12: Transport**

We know that accessible travel can enable people to enjoy a better quality of life, feel more connected to their community and reduce social isolation. However, we understand that there can still be barriers to transport and travel for neurodivergent people and people with learning disabilities.

Not being able to travel easily, comfortably and safely will impact many areas of life such as employment, education and access to health, social care and day services, and basic needs like getting shopping and socialising.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

An ambitious and wide-ranging programme of work is already underway to make improvements for disabled people when travelling, and this work is being informed and influenced by people with lived experience.

Whilst some aspects of transport are reserved to the UK Parliament and UK Government, there are some areas that we could explore in relation to the LDAN Bill:

#### **Proposal 1: National and Local Strategies**

Regional transport Partnership's (RTPs) were established to strengthen the planning and delivery of regional transport so that it better served the needs of people and businesses. They publish regional transport strategies specific to each region, supported by a delivery plan. RTPs bring together local authorities and others to take a strategic approach to transport in each region of Scotland. We could consider requiring RTPs to set out in their transport strategies how the specific needs of neurodivergent people and people with learning disabilities are being considered and met through travel information systems and accessibility initiatives.

We could also consider a requirement to set out in RTP travel strategies how staff across different modes of transport are being trained in disability awareness, how that training incorporates specific training on neurodivergence and learning disabilities, and the uptake of this.

#### **Proposal 2: Mandatory training**

Various actions and commitments around disability awareness training for transport staff are in place or are currently being progressed but is not a statutory requirement and is not necessarily consistent.

We have also set out in a previous section proposals for mandatory training for public sector staff on neurodivergence and learning disabilities, primarily in relation to health and social care staff, and have invited views on whether this requirement should be extended to other public sector areas. We could consider extending this requirement to transport staff in Scotland.

### What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

#### Proposal 1 National and local strategy

Including responsibilities of local authorities and funding panels with regards to ensuring that people have sufficient support to access activities and local transport services that facilitate this.

Responsibilities on local authorities where there the local infrastructure is insufficient. Provision of specialist transport.

Particularly in rural areas.

Will link with areas across the Bill.

A breadth of training is indicated, and we also agree with this (public sector equality duty to do so).

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to transport?

Impact of rural location on people who require support to access the community. Additional time and resource required to allow people to participate in community life and access community activities. Where support workers travel to meet the individual the time and cost of that travel reducing the time available for them and often further limiting access to meaningful and preferred activities.

For some people a lot of their support is taken up with the travel to and from an activity and may be further reduced by the travel time of support workers.

## Section 13: Education



This section relates to children and young people in early years, primary and secondary school education settings. Higher and Further Education and University education is considered within the scope of another section of the consultation, called Children and Young People -Transitions to Adulthood.

Neurodivergent children and young people, and children and young people with learning disabilities should be able to reach their full potential and live happy and fulfilling lives. Without the right learning experiences and support, these children and young people are likely to be disadvantaged, their quality of life adversely affected and their aspirations unreachd. This can be particularly felt by children and young people with profound and multiple learning disabilities for whom specialist education is the most appropriate option.

Neurodivergent children and young people, and children and young people with learning disabilities, their families, and organisations that represent them have consistently raised concerns that these groups are not having their right to education fulfilled and are missing out on reaching their full potential, which may contribute to poorer outcomes in adult life.

In Scotland, the education system aims to be fully inclusive. There is a legal presumption that children will be educated in mainstream schools except for in exceptional circumstances.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

An independent review of additional support for learning legislation found that the legislation is not deficient. However, it found a gap between the policy intention of the legislation and its implementation. Since then, a Additional Support for Learning (ASL) Review Action Plan has, and is currently being, progressed. This work is being done in partnership with Convention of Scottish Local Authorities (COSLA) and the Association of Directors of Education in Scotland (ADES). Whilst there is a comprehensive and robust action plan in place to address the implementation gap, the following proposals could potentially be explored in relation to the Bill:

#### **Proposal 1: Strategies and reporting requirements**

The 2000 Act imposes duties on education authorities and schools to plan and report annually on the measures that they are taking to address the key priorities of the National Improvement Framework (NIF). The statutory guidance to support these legislative duties is currently being reviewed. We could consider whether to create a new requirement for education authorities

and schools to include in their plans and reports an articulation of how the specific needs of neurodivergent pupils and pupils with learning disabilities have been considered and are being met.

We could consider whether to require that Children's Services Plans Annual Reports should include specific consideration of neurodivergent children and young people and children and young people with learning disabilities.

### **Proposal 2: Mandatory training for teachers, practitioners and other educators**

We have set out proposals for a mandatory training requirement for health and social care staff, and are seeking views on whether this should be extended to other public sector areas. Therefore, we could explore:

- (a) whether there is a need to set out anything in legislation regarding the training requirements for student teachers, given the recently updated Standard for Provisional Registration;
- (b) whether there is a need to set out anything in legislation regarding the training requirements for student Early Learning and Childcare (ELC) practitioners; and,
- (c) whether there is a need for a mandatory training requirement for teachers, practitioners and other educators on learning disabilities and neurodivergence as part of their Continued Professional Development (CPD).

### **Proposal 3: Data**

The overarching themes section of this consultation sets out broad proposals relating to data and invites views.

Current Additional Support Needs (ASN) data reflects that children and young people have a wide ranging spectrum of learning needs. Within this, there is disaggregated data available on some conditions but not others. For example, there is disaggregated data available on learning disabilities, autism and dyslexia but it isn't available on Attention Deficit Hyperactive Disorder (ADHD), and Fetal Alcohol Spectrum Disorder (FASD), Dyscalculia and other neurodivergent conditions.

To better understand all neurodivergent children and young people and their experiences and outcomes in relation to education this data could be collected and published. This would allow for reporting on the attainment gap of these groups, school leavers and positive destinations, and to understand the size of these populations and any trends. There may also be a need for data on the use of part-time timetables.

## What Do You Think?

Which of these proposals do you **agree** with (if any), please tell us why?

### Proposal 1 Strategy

A co-ordinated approach between health, social care, education and secondary care. Access to early assessment and specifically formal cognitive assessment that leads to clear diagnosis. Early intervention for range of physical, behavioural, emotional, educational needs. Streamlined approach towards transition beginning early in life. Recognising that current approach with educational psychology focus entirely on educational needs which does not look ahead to adulthood has led to people not being diagnosed until adulthood, significant missed opportunities, wide unmet need and exploitation and abuse; links to annual health checks and patient passports and; involvement of families and consideration of their needs.

### Proposal 2

Mandatory training supported by access to assessment

### Proposal 3 Data

Yes

With possibility of extending annual health checks and DSR reporting to support local strategy, commissioning, whole life approach, transitions

Which of these proposals do you **not agree** with (if any), please tell us why?

Is there anything else that we should consider in relation to education?

We note progress being made in South America:

[Education for All: Advancing Disability Inclusion in Latin America and the Caribbean \(iadb.org\)](http://iadb.org)

“Overcoming the main barriers to education inclusion can be accomplished through: (i) improving early identification of children with disabilities; (ii) strengthening data on school accessibility; (iii) implementing universal standards for accessibility and earmarking schools with higher needs with additional resources to support reasonable accommodation; (iv) training teachers and providing trained aides”

## Section 14: Children and Young people – Transitions to Adulthood

The term ‘transitions to adulthood’ will mean different things to different young people, and as such will be achieved in many different ways and timescales.

In their Principles of Good Transitions, The Association for Real Change (ARC) Scotland refer to this as the period when young people develop from children to young adults. This is not a single event, such as leaving school, but a growing-up process that unfolds over several years and involves significant emotional, physical, intellectual and physiological changes. Transitions also impact on the family of, or those who care for, the child or young person.

### **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

In their Stage 1 Report on the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Member's Bill, the Education and Skills Committee noted that many people have described the current legislative landscape as being complex, cluttered, and difficult to navigate for young people and their families, and, in some instances, for the professionals working to support them.

The Committee's report concluded that "... the Committee is not yet convinced that introducing further legislation in an already cluttered and complex legislative and policy landscape will resolve the issues...". Rather, there was thought to be a "significant implementation gap between the [existing] intended policy and the experiences of children and young people." In the Stage 1 debate on the general principles of the Bill, on 23 November 2023, the Bill fell and so will not become law.

Transitions is a period of development which can involve changes in every area of life such as housing, employment, social care, education, transport and relationships. We therefore expect some of our overarching and specific consultation proposals, which covers all of these areas and more, to contribute towards improving outcomes for neurodivergent young people and young people with learning disabilities making the transition to adulthood. This also includes our proposals around inclusive communications, mandatory training, independent advocacy, and statutory strategies for learning disabilities and neurodivergence.

Specifically in relation to data, we will consider whether our approach ensures that disaggregated data for neurodivergent young people and young people with learning disabilities is made available to:

- enable us to better understand and measure the extent to which these young people are experiencing a positive and supported transition to young adult life;
- ensure the visibility of these young people;

- help inform the work that will take place under a National Transitions to Adulthood Strategy; and,
- help to inform the development of services to meet the needs of these young people when transitioning to adulthood.

## What Do You Think?

Do you **agree** with this proposal, please tell us why?

Local authority responsibilities regarding data for children and young people.

To support planning and commissioning of services.

Recognising the time that it takes to develop services and that commissioning tends to look only towards current level of need and not ongoing and future need.

Whole life approach to reduce health inequalities across the lifespan.

Ensure access to early assessment and interventions across relevant services.

Reduce morbidity into adulthood.

Better transitions.

Do you **not agree** with this proposal, please tell us why?

Is there anything else that we should consider in relation to Children and young people – Transitions to adulthood?

Preparation for transition should be considered as beginning early in life.

Early consideration of learning disability and autism leading to prompt assessment to support early intervention.

Clear evidence that there is a significant proportion of people who do not have their learning disability diagnosed until after they reach adult services.

Historically children and young people had formal cognitive assessment undertaken by educational psychology where there were concerns about the possibility of learning disability. This is no longer undertaken by educational psychology services whose focus is on educational support needs and attainment, rather than diagnosis which might inform a whole of life approach and focus attention on a more seamless transition to life as an adult with a range of opportunities.

Neuro developmental pathways for children and young people have been developed in some areas and there has been progress with regards to access to autism assessment, support and treatment for CYP.

National strategy prioritising early assessment, access to formal cognitive assessment at all ages to support early diagnosis, early intervention, prevention regarding health inequalities, in keeping with MH and Well-being strategy leading to preparation and planning towards streamlined transition to adult life.

For some adults with learning disability and autism the initial move to an out of area placement begins in childhood or adolescence when they move to a specialist residential educational setting. They may become lost to services until they turn 16 or 18 when they may be returned to their board of origin with no planning and without an identified service that could meet their needs.

In some areas no access to CAMHS LD specialist services leads to higher levels of morbidity as progress into adulthood and high levels of acuity and morbidity presenting to adult LD services.

In some areas the numbers of young people with LD and autism being treated in CAMHS services is far smaller than would be expected given the increased risk of mental ill health which suggests significant diagnostic overshadowing and that the barriers to care are as much of an issue in CYP.

Evidence that some young people get stuck in adolescent residential services awaiting an appropriate adult service. That they have outgrown the adolescent service and that it is often inappropriate that they remain amongst a group of often much younger peers, leads to increasing frustration, distress, increasing restrictions and can lead to behaviours that challenge that can make finding an appropriate adult service even harder and require more intensive packages of support and care.

It would be valuable to extend data collection and reporting via DSR to children and young people, with some modification that recognises out of area placement in residential educational settings, admission to local children's and adolescent units and delayed discharge at the time of transition to adult services.

It would be valuable to evaluating whether annual health checks should be extended to children and young people with learning disability and autism. Whilst recognising that there will be a smaller group of CYP with LD&A with additional health needs who regularly access paediatric health services due to genetic conditions, epilepsy, physical health conditions, cerebral palsy etc.

It would also be helpful to understand when people with learning disability and autistic people access CAMHS services and for what reasons. In some areas it is evident that few young people with learning disability and autism access CAMHS services despite the fact that they are at increased risk of mental ill health. A better understanding as to potential barriers to care, diagnostic overshadowing and mental health needs is required.

Commissioning of services and adequate time to plan for this in advance is important and may be improved by also extending DSR data gathering from the time that a young person is diagnosed with learning disability or autism.

Ensuring that there is adequate local support to the person and family which anticipates transition and prepares for this in good time recognising that establishing services for people can take considerable length of time to do well and to reduce distress, confusion and isolation.

Trauma informed services

Managing bullying and stigma and a culture shift to involving and valuing people with lived experience

[Invisible no more: Learning disabilities in Scotland | FAI | FAI \(fraserofallander.org\)](#)

“The Scottish Government should ensure that reforms, including No One Left Behind and the National Care Service, provide specific proposals that ensure changes made will improve transitions for young people with disabilities. The implementation of these changes should be monitored and the experience of young people with disabilities during the transition period should be routinely captured as part of monitoring and evaluation”.

## **Part 4: Accountability**

Throughout our early work we have heard many different views on how people think their rights can best be enforced. One thing most people with learning disabilities and other neurodivergent people agree on is that they often have trouble knowing what their rights are and being able to properly access their rights. Most people would like to see more accountability to make sure rights are not ignored.

When thinking about accountability, people like different models – some people want to see a new body to enforce rights and some people want to see greater accountability within existing public bodies or a specific role within

an existing human rights body, such as the Scottish Human Rights Commission.

## **What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?**

The Bill can be used to ensure that there is improved accountability for the delivery of rights. There are different ways to do this and we have set out some options.

### **Option 1: A new Commission or Commissioner**

A Commission or Commissioner could be set up to help people secure their rights. A Commissioner is one person whereas a Commission might have a board with several people on it.

Either of these would be set up to be independent of Government and its powers and duties and appointments process could be set out in the Bill. These could include the following:

- Consult and involve neurodivergent people and people with a learning disability in the appointments process and work programme,
- Promote human rights,
- Conduct research,
- Hold the Government to account,
- Hold public bodies to account by conducting inquiries and formal investigations,
- Power to bring court proceedings,
- Publish an annual Strategic Plan and financial accounts,
- Collate and publish data and report regularly to the Scottish Parliament on key outcomes for neurodivergent people and people with learning disabilities

### **Option 2: Better resourcing and additional duties for an existing Commission or Commissioner**

Neurodivergent people and people with learning disabilities already come within the remit of the Scottish Human Rights Commission (SHRC), the European Convention on Human Rights (EHRC), the Children and Young People's Commissioner and other more specialist bodies like the Scottish Public Services Ombudsman (for public service complaints) and the Mental Welfare Commission.



However, these bodies cover the needs of a broader range of people than those with neurodivergence or learning disabilities. This means that they have to take decisions on where to spend their resources and time and prioritise some issues over others. We know that the needs of people with learning disabilities and neurodivergent people are often not being met even though these bodies are doing many good things. But there is not a specific focus on these groups.

Rather than setting up a new body we could look to our existing bodies and provide additional resources and potentially powers and duties that would allow them to play a more comprehensive role in upholding the rights of neurodivergent people and people with learning disabilities.

We would need to decide which body could best do this. The Bill could amend the legislation that established the body chosen.

### **Option 3: Champions and Advocates within Public Bodies**

Scotland has many public bodies whose roles are central to the experiences that neurodivergent people and people with learning disabilities have in their daily lives as they have responsibility for administering many key areas of life such as education, health and social care, and justice.

This option could involve having people with lived experience of neurodivergence or learning disabilities, or people selected by people with lived experience of neurodivergence or learning disabilities, raising awareness of rights within public bodies and promoting a culture where the rights of neurodivergent people and people with a learning disabilities are upheld.

Public bodies include local councils, healthcare providers like the National Health Service (NHS), the Police and many other bodies.

We could explore the potential for the Bill to make provision for this role to be appointed within all Scottish public bodies and could clarify the remit and appointments process.

### **Option 4: Better resourcing for existing Disabled People's Organisations who support neurodivergent people and people with a learning disability**

When we refer to Disabled People's Organisations (DPOs), we mean those organisations that are led by disabled people themselves. They are directly connected to the communities that they support.

In Scotland, many DPOs receive funding from local councils or the Scottish Government. DPOs include Autistic People's Organisations (APOs) in Scotland (there are several) and People First, which is an organisation led by people with learning disabilities.

This option would mean better resourcing of existing DPOs to allow them to support and advocate for the rights of neurodivergent people and people with learning disabilities.

Although the Scottish Government and other organisations already fund DPOs, including some APOs and People First, funding can be limited or directed at particular projects or policies. We know that DPOs work very hard on behalf of the people they represent and have knowledge and understanding of the issues that often come from their own experiences.

### **Option 5: Supporting good practice through standards, guidance and practical tools and investing in co-production**

This could involve us working continuously with people with lived experience (like the Lived Experience Advisory Panel (LEAP)) to produce national standards and guidance to help people understand the needs and wishes of neurodivergent people and people with learning disabilities and uphold their rights.

It could include providing guidance to schools, universities, councils, healthcare providers, the police, and others. However, we already do this kind of work and there are still many serious issues experienced by people with learning disabilities and neurodivergent people. This guidance, and accompanying tools, could help people within these organisations understand how to respect the rights of neurodivergent people and people with learning disabilities.

### **What Do You Think?**

Which of the 5 options set out above do you think would best protect, respect and champion the rights of neurodivergent people and people with learning disabilities? You can select multiple options if you wish.

- Option 1
- Option 2
- Option 3
- Option 4

Option 5

Please give the reason for your choice(s).

### **Option 2 The role of the Mental Welfare Commission for Scotland**

The Mental Welfare Commission for Scotland (the 'Commission')) is a public body established under Part 2 of the Mental Health (Care & Treatment) (Scotland) Act 2003 ('the 2003 Act) to protect the human rights of people with mental illness, learning disability, dementia and related conditions.

Our Mission is to "be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice" is in keeping with many aspirations of this consultation.

The Commission's strategic priorities include a focus on the most vulnerable. People with LD/ autistic people who have additional mental ill health and require support for decision making or where they are unable to make decisions about their health and well-being when appropriate support has been given and are subject to detention in mental health settings and subject to restrictive interventions are amongst the most vulnerable in our population.

The Commission has an established role and statutory reporting systems.

It is recognised nationally as an organisation concerned with protecting the rights of people with LD&A when subject to mental health and capacity legislation.

This is evidenced through the activities of the Commission which are discussed below:

#### **Phone advice line**

The Commission, within the remit of the 2003 Act 2003, Sections 9 and 10, operates an advice line, open to professionals as well as individuals and carers/ relatives/welfare guardians. The advice line receives about 4000 calls each year. service evidencing our desire to be a centre of expertise fulfilling our role as per legislation. We give information and advice about rights and best practice specifically in relation to the Mental Health (Care & Treatment) (Scotland) Act 2003, the Adults with Incapacity (Scotland) Act 2000, and the Adult Support and Protection (Scotland) Act 2007.

What do people call the Commission about?

This review showed that calls related to a wide range of topics that were diverse and difficult to categorise. A higher proportion of calls to the advice line come from non-professionals, just under half of the calls related to legal issues and 13% of all called related to ethical issues, 6% to moral issues and 4% were about financial issues. The advice line serves a wide range of people phoning about many different topics and suggests that this unique service provided in Scotland is a point of call for many to get independent advice about ethical, legal and general issues related to mental health.

[2022-04\\_AdviceLineCalls-brief.pdf](#)

### Monitoring the Acts

[AWI-MonitoringReport 2022-23.pdf \(mwscot.org.uk\)](#)

[MentalHealthAct MonitoringReport 2022.pdf \(mwscot.org.uk\)](#)

### Designated Medical Practitioner & Nominated Practitioner Service

### Published Guidance

The Commission produces good practice guides to support best practice across a wide range of areas of interest such as social circumstances reports, excessive security, tenancies, advocacy and supported decision making. The Commission website also provides answers to questions that individuals who have experience of care and treatment, members of the public, carers, and professionals have asked us.

### *Rights in Mind*

This pathway is designed to help staff in mental health services ensure that patients have their human rights respected at key points in their treatment.

[Rights in Mind | Mental Welfare Commission for Scotland \(mwscot.org.uk\)](#)

### *Rights Risks Limits to Freedom*

The Commission have produced a range of guidance for health and social care services looking at the legal, ethical and practical considerations which must be taken into account when restrictive interventions or limits are to be placed on someone's freedom of movement.

Rights, risks, limits to freedom

[mwscot.org.uk/sites/default/files/2021-](#)

[03/RightsRisksAndLimitsToFreedom\\_March2021.pdf](#)

### *Use of Seclusion*

[Seclusion\\_GoodPracticeGuide\\_20191010.pdf \(mwscot.org.uk\)](#)

*Authority to discharge: Report into decision making for people in hospital who lack capacity 2021*

[AuthorityToDischarge-Report\\_May2021.pdf \(mwscot.org.uk\)](#)

### *Right to Treat*

When someone lacks the capacity to provide consent, it is vital to ensure that there is a clear basis on which treatment takes place both for the healthcare professional providing the treatment and to safeguard the rights of the person. This guidance provides information to determine the basis on which to proceed or not.

[Right to treat \(mwscot.org.uk\)](#)

### *Vaccination for people with mental illness, learning disabilities, dementia and associated conditions*

Research has shown that people with mental health difficulties that might underlie reduced capacity are at greater risk of Covid-19. The concern is that people who are unable to consent to the vaccine and are resisting should not be disadvantaged because of any uncertainty about how to proceed in these situations. The wish to ensure that people who are resisting vaccine due to a lack of capacity to consent are treated with dignity and in accordance with the principles of the 2000 Act led to review and update the guidance note for practitioners.

[CYFARFOD BWRDD IECHYD \(mwscot.org.uk\)](#)

### Guardianship visits

During 2022-23, we visited 205 individuals on a guardianship order (98.1% in person and 1.9% virtually). Most were routine visits (77.6%), while 17.6% were due to concerns that had been raised. 100 people with learning disability and 40 autistic people were visited in the last year.

During our visits, we look for examples of the principles of the AWI Act and of rights in line with human rights conventions. We already consider key aspects of the UNCRPD to demonstrate the adult is supported to exercise their rights in relation to all aspects of their lives. This might include elements of supported decision making to allow them to participate and make the decisions they are able to make for themselves. Proxy decision makers, like guardians have the power to make certain decisions in the absence of the adult but they must demonstrate they have taken the adult's will and preferences into account.

The Mental Welfare Commission has recently expanded their visiting to include Community Learning Disability Team visits with the aim of developing a greater understanding of the care and treatment available to people in those services.

### Themed visits

The Commission has recently completed visits to individuals in specialist services out of NHS Scotland. This includes people with learning disability and autistic people subject to delayed discharge and continues the work undertaken in the No Through Road report (see below).

[OutOfNHSArea-ThemedReport\\_20230907.pdf \(mwcscot.org.uk\)](https://www.mwcscot.org.uk/OutOfNHSArea-ThemedReport_20230907.pdf)

*Autism and complex care needs. October 2019.*

This was a themed visit specifically looking at support for autistic people. 54 people were visited in hospital and community settings, including specialist autism services in England. Carers and professionals were involved. There were recommendations to:

*NHS Boards:* to ensure that people with autism have comprehensive assessment and diagnosis and individualised environmental and sensory assessments whenever a person with autism is admitted to a psychiatric setting.

*Integration Authorities:* to have a dedicated care co-ordinator overseeing evidence-based treatment via a tailored activity plan, support for families with the offer of a carers assessment, post diagnostic support with involvement of people, carers and families and arrangements to secure community provision for people with autism in hospital within 6 months of their being assessed as able to be supported in the community.

*The Scottish Patient Safety Programme:* to develop a programme to reduce the use of psychotropic medication for autistic people for the management of behaviours perceived as challenging and to reduce levels of restraint.

*NHS and community services:* to maintain policies regarding the use of restraint and seclusion and to develop improvement plans to reduce their use.

*Scottish Government:* to monitor delivery of the above recommendations.

There were additional recommendations across services regarding training needs and clinical supervision of people providing services to people with autism and complex needs.

[ASD\\_ThemeVisitReport-20191030.pdf \(mwcscot.org.uk\)](https://www.mwcscot.org.uk/ASD_ThemeVisitReport-20191030.pdf)

### Investigations and casework

Section 11 of the 2003 Act gives the Commission the authority to carry out investigations and make recommendations, as it considers appropriate, in situations where an individual with mental illness, learning disability, dementia or related condition may be, or may have been, subject to ill treatment, neglect or some other deficiency in care and treatment.

When there is such a concern, we report these to the people most directly responsible and ask them to take any action required. If we do not get a response, we will escalate

this request to management level. Where an issue is very serious, and is not resolved by the services involved, we can escalate our concerns right up to Scottish Ministers.

The Commission undertakes a range of inquiries and investigations, the majority of which are not published but are resolved through casework and working in partnership with the individual, their relatives, and the service.

The Mental Welfare Commission Investigations group have investigated the treatment of people with learning disability and autism where there have been concerns about deficiencies in the care they received from health and social care services.

We may instigate a full-scale investigation where we recognise a deficiency in care or significant harm that has implications and shared learning for services across Scotland. The intention of Commission investigations is to share learning at local and national level, to support improvement and therefore outcomes for individuals irrespective of whether the investigation was carried out in their specific health board or local authority area.

Themes highlighted through investigative work relate to initial assessment and care planning, risk assessment, communication, knowledge and training, leadership and staff supervision, integration and dispute resolution and transitions in care and treatment. Recommendations for learning and improvement that have resulted range from local and national recommendations. Taking account of recommendations made over the past 10 years we find different circumstances yet some similar recommendations relating to review of local policies and procedures, audit and evidence gathering, training issues, care plan and risk documentation and formal apology and duty of candour.

[LearningThroughReview-SummaryOfOurInvestigativeRole June2022.pdf](https://www.mwcscot.org.uk/learning-through-review-summary-of-our-investigative-role-june-2022.pdf)  
([mwcscot.org.uk](https://www.mwcscot.org.uk))

*Investigation into the care and treatment of AB. August 2023.*

The recent Commission investigation report into the care and treatment of AB, a vulnerable person with learning disabilities and physical ill health, who died in hospital after being under the influence of another individual for many years and despite multi-agency concerns about the impact of this influence. The report illustrates the importance for health and care professionals of fully assessing an individual's capacity for decision-making; balancing human rights and considering the potential for undue influence.

The Mental Welfare Commission makes six recommendations for change jointly to the NHS health board and local authority involved in this case, and one recommendation to Scottish Government.

[InvestigationIntoTheDeathOfAB\\_20230803.pdf \(mwcscot.org.uk\)](#)

### Advisory Committee

The statutory Advisory Committee informs the work of the Commission in the learning disabilities and autism fields with representation from national bodies including Enable, Learning Disability Nurses Forum, National Autistic Society and the Scottish Human Rights Commission.

### Sharing Intelligence for Health and Social Care Group

The Commission shares information with other key scrutiny bodies such as the Care Inspectorate (CI) and Healthcare Improvement Scotland (HIS) through regular meetings of the Sharing Intelligence for Health and Care Group. This is a mechanism that enables seven national agencies to share, consider, and respond to intelligence about care systems across Scotland (in particular NHS boards) and the information shared helps decide where we should prioritise our visits.

As well as being published on our website, copies of all our local visit reports are sent to the CI for visits to care homes and to HIS for NHS services and independent hospitals. Copies of our reports to prisons are sent to HIS and HM Inspectorate of Prisons. We want to make sure that these organisations are aware of any concerns that we have raised as they may choose to look further at these.

The Commission is further developing its visiting role in collaboration with the CI, HIS and the Scottish Human Rights Commission where there is combined intelligence that supports specific combined visits.

### UK National Preventative Mechanism (NPM)

The Mental Welfare Commission is a member of the UK National Preventive Mechanism (NPM). The NPM was established in 2009 to strengthen the protection of people in detention through independent monitoring. Our local visits, where we visit in-patient units where people may be detained, and our visits to mental health services in prisons, link with our role as an NPM member. In coordination across the four nations of the UK, the NPM focusses attention on practices in detention that could amount to ill-treatment and works to ensure its own approaches are consistent with international standards for independent detention monitoring.

### Enhanced role of Mental Welfare Commission



The role of the Mental Welfare Commission for Scotland could be extended and enhanced to further safeguard the interests of people through the intentions of the proposed Bill as an interim measure whilst progress is made towards the Scottish Mental Health Law Reform.

This could happen in parallel with National Strategy and in collaboration with other public bodies and commissions.

Areas where the role of the Mental Welfare Commission could be strengthened include:

#### MHA Monitoring

Strengthen requirements around completion of recording of diagnostic categories with an additional option to code autism under mental disorder in addition to mental illness, personality disorder and learning disability.

Monitoring of restrictive practice for people subject to the 2003 Act a new statutory notification for people subject to seclusion, restraint, segregation or covert medication requiring notification and review in keeping with providing authority for medical treatments;

this could be associated with a notification process in some situations building on our existing work with regards monitoring through statutory and non-statutory notifications.

Notification to MWC when a person with LD or autism is admitted to hospital and is not considered to have any additional mental health conditions and leading to a Mental Welfare Commission visit for any individual with LD or autism who does not have any additional mental health conditions where they remain in hospital beyond 2 months;

Notification to MWC when a person with learning disability and/ or autism is admitted to a non-learning disability specialist service (whilst recognising that depending on an individual's specific needs admission to a general psychiatric service may be appropriate) where this may lead to a Mental Welfare Commission visit should an initial review highlight that the care and treatment needs of that person are not adequately met in that environment.

Notification to MWC by DSR/ other where a person remains a delayed discharge beyond a set time frame as outlined in National Strategy and detailed in local care plans.

#### AWI Monitoring

Monitoring of a new statutory notification of use of restrictive practice for people subject to AWI seclusion, restraint, segregation or covert medication.

### Advice line

One idea from the recent panel process was to have one single place that people with learning disability and autistic people can go to when they have concerns about their care and treatment or feel that their human rights are being infringed. This could develop from the Commission advice line where anyone has a question regarding the use of mental health or incapacity legislation for people with learning disability and autism where there might also be human rights concerns.

### Visits

Inquiry by the Commission when a person is subject to the 2003 Act due to learning disability or autism alone leading to a visit by Commission when such a detention raises a concern or extends beyond a certain point (through monitoring processes as mentioned above).

### Guidance

Additional requirements that the MWC produce Good Practice Guidance regarding the use of other restrictive interventions including seclusion in special situations (long term segregation, solitary confinement, isolation etc.) that are specific for or meet the needs of people with LD and Autism.

### Investigations

Review of the care and treatment of people with learning disability and autistic people who die in mental health settings and/ or subject to mental health legislation. We could undertake a more focussed review (as per LeDeR) on a recurring basis of the themes that are associated with people with learning disability who die subject to the mental health act with recommendations.

### Collaboration with other organisations

Whether there is a new commission/er or strengthened roles for existing organisations there will be a need for existing commissions/commissioners and organisations to work together to realise the hopes from the bill/consultation with clear leadership and communication systems.

Are there any other options we should consider? Please give details.

Statutory National Strategy which establishes a senior Scottish Government adviser or director for LD&A may be helpful in providing high level oversight and leadership with regards to the identified priorities of a Learning Disability and Autism Bill and their implementation. To be effective there would need to be clear links across government given that the breadth of the intentions of the Bill across physical health, mental health and social care. Clear links with lived experience groups, safeguarding bodies and organisations will also be important.

### Scottish Mental Health Law Review (SMHLR)

We note the SG response to the SMHLR and the commitment to take forward priority areas, including AWI reform. A number of the recommendations arising from the SMHLR were raised through the LDAN consultation process by the lived experience and stakeholder panels as key areas and we would suggest that are considered through the LDAN process.

Recommendations relating to the role of the Commission include:

- Supported decision making “Respect for the full range of the rights, will and preferences of everyone must lie at the heart of every legal regime. That must be achieved regardless of the existence and nature of any disabilities”
- Deprivation of liberty & reducing coercion “MWC monitoring and reporting on the use of restraint, seclusion and covert medication, whether authorised by MHA or AWI with the ability to intervene and challenge the lawfulness of a deprivation of liberty”.
- Authority to compel “The Mental Welfare Commission’s powers to request information and co-operation from other authorities should be amended explicitly to cover any organisation with which it needs to collaborate for the purpose of these investigations”
- The Mental Welfare Commission and advocacy groups should develop a participatory referral process to escalate human rights issues that remain unresolved and unaddressed by services to the Mental Welfare Commission to investigate and, if appropriate, initiate legal action.
- Right to appeal against being subjected to unjustified restrictions akin to excessive security.
- Children and adolescents “We received a lot of evidence that autistic children and children with other neurodevelopmental differences (such as ADHD) were particularly poorly served by the care and support on offer in mental health services, and that CAMHS were not designed with their needs in mind”.
- Adults with Incapacity Act “Greater safeguards and challenge re decisions as to incapacity under section 47. Currently no dispute resolution process. Greater safeguards are required for the adult, who may find it difficult to access and instruct an application to the sheriff”.

Role and functions of the Director of Learning Disability and Autism in NHS England and benefits that could be gained from that model.

[NHS England » Learning disability and autism programme update](#)